DOCUMENT RESUME

ED 170 510 CE 020 417

AUTHOR Murphy, Ruth
TITLE Why Minority Individuals with Developmental Disabilities Drop Out of the Service System. A Report.
SPONS AGENCY Wisconsin State Council on Developmental Disabilities, Madison.
PUB DATE Nov 78
NOTE 142p.
AVAILABLE FROM Christina Metzler, Information Section, Division of Community Services, 1 West Wilson Street, Room 561, Madison, Wisconsin 53702

EDRS PRICE MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS *Delivery Systems; *Developmental Disabilities; *Handicapped; *Minority Groups; *Personnel Evaluation; Problems; Program Effectiveness; Program Evaluation; Research; Sensitivity Training; Staff Improvement; *Staff Role; Surveys
IDENTIFIERS *Service Systems; Wisconsin

ABSTRACT

An instrument was developed to obtain data relevant to why minorities with developmental disabilities drop out of the service delivery system in Wisconsin. The questionnaire, after being pre-tested and revised, was sent to agencies, organizations, and schools, and to individuals with developmental disabilities who agreed to participate in the survey. Results of this investigation indicated that developmental disability staff working with minority individuals with developmental disabilities were viewed as "insensitive." Moreover, minority clients were in need of services such as transportation and babysitting. Recommendations included (1) workshops for staff and clients to improve communications; (2) ongoing minority sensitivity training programs; and (3) training and education programs for developmentally disabled individuals with a definite future in mind. (Surveys--pre-test, final, and correction--and data tables are included.) (CT)

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A REPORT

WHY MINORITY INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES DROP OUT OF THE SERVICE SYSTEM

U S DEPARTMENT OF HEALTH, EDUCATION & WELFARE
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RESEARCH ANALYST

Funded by the Wisconsin Council on Developmental Disabilities under P.L. 94-103

November 1978

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ACKNOWLEDGMENT

I (Ruth Murphy, Research Analyst) wish to acknowledge my sincere gratitude to all of the state and local agencies, organizations, and individual participants who made this project possible. The Council extends its appreciation and support to the following individuals.

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Joanne Cowling
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CHAPTER I

INTRODUCTION

The Rehabilitation Act of 1977, Section 504 was originally enacted to protect the civil rights of all handicapped Americans. Section 504 was designed to reach in a pervasive way those situations where equal opportunity is not afforded handicapped individuals, and to alter the discriminating conditions. The regulations now stipulate, however, that the termination of discriminatory treatment is not always an adequate means of redressing the resulting damage. Coincidental with the cessation of discrimination must be positive action that will take into consideration the handicap itself, in order to ensure equal opportunity.

Moreover, it may be instructive to note that Section 504 regulations address issues of primary importance to the well-being of handicapped individuals, issues of education, employment, access and use of facilities and social services.

Of paramount importance to the successful implementation of Section 504, especially as it affects minority individuals with developmental disabilities, is adequate knowledge about minority individuals so that equality of opportunity may, indeed, become a reality.

Part of the current situation is the issue of minority drop-out. Observers in numerous agencies and organizations have indicated that although minority individuals enter the service delivery system, many leave the system prematurely. Consequently, these individuals do not receive the maximum help

needed. The purpose of this study was to investigate why minority group members with developmental disabilities drop out of the service delivery system.

A review of the literature regarding the drop-out issue was made as well as a pilot survey of minority clients who had left the service delivery system. Moreover, a comprehensive survey of minority individuals with developmental disabilities was made. The objectives of this latter study were:

1. To determine if the individual with a developmental disability ever encountered any problems in the service delivery system.

2. To determine if the individual with a developmental disability ever refused any help from the service delivery system.

3. To determine what help, if any, the individual with a developmental disability needs from the service delivery system.

4. To determine how the individual with a developmental disability finds out about the service delivery system.

5. To determine how the individual with a devleopmental disability feels about the DD staff.

LIMITATIONS

The following factors will limit the study:

1. The study is limited to minority individuals (Blacks, Native Americans, Hispanics, and Asians.)

2. The study is limited to the State of Wisconsin.

3. The study is limited to all agencies, organizations and schools willing to participate in the study.

4. The study is limited to individuals diagnosed as having one or more of the developmental disabilities (cerebral palsy, mental retardation, epilepsy, and autism).

5. The study is limited to minority individuals with developmental disabilities who dropped out during the 1976-77 school year or the 1976 calendar year, and/or to individuals diagnosed as having one or more of the developmental disabilities but for some reason are not receiving needed services.

6. The study is limited to individuals willing to participate in the study.

CHAPTER II

REVIEW OF LITERATURE

In reviewing the literature, little information was found on studies pertaining to minority individuals with developmental disabilities who drop out of the developmental disabilities delivery system. More information was found, however, when viewing the drop-out issue without regard to individuals with developmental disabilities. Researchers at George Washington University (1975) indicate that dropping out is a symptom of the real problem; they further contend that the roots of the problem are usually below the surface.

Much has been written regarding the profile of individuals who tend to drop out of school. In an ESEA Title III project in St. Paul, Minnesota, researchers characterized the student who is "disaffected" or drop-out prone as: (1) one who is unable to function properly within the traditional classroom setting; (2) one who is generally recognized as an underachiever (below average in performance when compared with ability); (3) one who fails to establish goals regarding his future occupations; (4) one who has a record of tardiness as well as absenteeism; (5) one who lacks motivation, direction, and drive; (6) one who comes from a stressful family situation which appears to have a detrimental effect; (7) one who is hostile toward adults and authority figures; (8) one who is generally not involved in any school activities; (9) one who has difficulty with community agencies and the law; and (10) one who has serious economic problems which threaten the completion of school.

Additionally, according to researchers at George Washington Universiy in the special report, the drop-out is most often a boy who frequently leaves school at the age of 16 while in the 10th grade. The boy is more likely to score low on an intelligence test and he is often one or more years behind in grade placement as well as failing in school at the time he drops out.

Moreover, the special report further points out that individuals who drop out are really not less intelligent, but rather typically come from low-income families and most often leave school for financial reasons. Like the ESEA Title project, the report by researchers at George Washington University points out that the drop-out has absences from school, that the absenteeism increases noticeably during the 8th grade, and that the drop-out participates little or not at all in extracurricular activities.

Although it was not mentioned by the special report by George Washington University and the ESEA Title Project, researchers such as Siegel (1974), Grier and Cobbs (1974), Vantress (1971), Calnek (1970), Dubey (1970, Brieland (1969), Burrell and Rayder (1971), and Barnett and Perlmutter (1972) indicate that there might be certain barriers that exist between the white provider and the black client that eventually lead to the drop-out of the black client.

Jerome Siegel (1974) in his discussion concerning the white therapist and the black patient indicated that clinical speculation about the factor of race in psychotherapy and counseling has been concerned largely with possible barriers between the black patient and the white therapist. He indicates

that perhaps the most frequently mentioned barrier is the black patient's pervasive distrust of the entire white world. According to Vantress (1971), this is called the "Negro Self-Disclosure Reserve," or the black patient's unwillingness to reveal himself to a representative of the white world. On the other hand, Adams (1970) sees the white therapist's unconscious (or conscious) racism as a barrier to successful interracial therapy. This researcher indicates that racism is causing strong negative counter-transference reactions that interfere with successful outcome in psychotherapy. Adams further points out that the remedies for the racist-based counter-transference is for the therapist, himself, to undergo personal treatment.

Differing cultural backgrounds of the white therapist and the black client also have been a barrier resulting in the black patient not only suffering from a communication gap, presumably encountered by any lower-class patient dealing with a middle-class therapist, but from a special gap caused by the white therapist's inability to comprehend the idiom of the ghetto as well as his total ignorance of black mores and culture.

Grier and Cobbs (1974) noted that distortion caused by the sympathetic and aware white therapist who focuses so closely on the successful and pathogenic background of ghetto life that he cannot bring the individual psychopathology into clear focus against his background is also a barrier to providing services to black patients. Vantress (1971) points out that another barrier to providing services to the black client is that the white therapist is viewed by the black client as the enemy while the black therapist is often seen as something worse, the enemy's collaborator. Calnek (1970) mentions the possible tendency of the black therapist to imitate the white middle

class and to put as much psychological distance as possible between himself and the lower class black patient.

Another researcher, Dubey (1970), did a survey in a black Cleveland neighborhood in which he asked the question, "Would you like to talk to a Black social worker?" Dubey found that black respondents did not prefer to patronize blacks over whites as occupants of various social roles. In similar research done in Chicago by Brieland (1969), a different view was found. When black clients were interveiwed by black service providers (doctors, teachers, and lawyers) and when the questions were presented so that the black or white service providers were equally competent, black preference for black service providers was supported. Moreover, black preference for black doctors was the strongest, whereas black preference for black lawyers was the weakest.

Burrell and Rayder (1971), in their study found that black high school students were less favorable about being counseled by white counselors than were white students.

Barnett and Perlmutter (1972), in their study made the distinction between the intake interviewer and the actual interview. According to these researchers, the black client might benefit more from an intake with a fellow black, although once in the system, a competent white counselor might serve equally as well as a black counselor.

It is quite evident as reflected in the literature that the relationship between client and therapist is of paramount importance. More importantly

for the sake of our discussion, the relationship between a white therapist and a black client is equally important, if not more important, because of the tremendous damage that blacks historically have experienced.

LaFargue (1972), in working with nurses, found that if white nurses are to help the black family, they must understand the dynamics of prejudice and its effect on their own behavior. Rosen and Frank (1972), further elaborate on the white nurse-black patient relationship. They point out that the white nurse must be alert to the possibility of her own unconscious racial prejudice through which she may subtly reject black patients so that they, in turn, reject medical care.

Allport (1972), suggests that intimate relationships and equal-status contacts are the best reducers of prejudice. However, D'Onofrio (1966), in researching a hard-to-reach unvaccinated population, reported that an individual's utilization of health serivces depends, in part, upon the direct and indirect experiences previously encountered between the individual and the agency.

Continuing in the same vein, other studies comment on the issue of client-therapist relationship. Hollingshead and Redlich (1958), mention that the early termination by blacks could be due to the difficulties in establishing trust, rapport, and a working relationship between therapist and clients differing in race, social class, or life style. Carkhuff and Pierce (1967) assigned clients to therapists who were similar or different in race or social class. Their finding indicated that clients' self-exploration was significantly lower when the therapists differed from clients on these two

variables. Their study further points out that clients also tend to prefer working with the same-race therapists. Schofield (1964) argued that therapists often select clients for therapy on the basis of characteristics that would place blacks and the poor at a disadvantage.

Sue, McKinney, Allen and Hall (1974), indicated that their research suggests that the delivery of service is particularly unresponsive to black Americans. These authors point out that race has been a barrier in admission policies to mental hospitals and that there still appears to be an overrepresentation of blacks in public versus private mental health facilities.

These researchers further emphasize that mental health centers should examine their policies of staff assignments and pay increased attention to the termination rate of black clients. These authors also mention that discrimination against blacks in the mental health system still exists, albeit in subtle ways.

Cornely (1976), also speaks to the issue of racism. This author indicates that racism is one of the most important barriers in our society to the attainment of health and the delivery of health care and other human services. Its cost in wasted human resources, human lives, and human degradation, as well as its warping effects on those who practice discrimination and segregation, must run into the billions of dollars each year.

According to Cornely, his research addressed questions that have been raised persistently and continually in the public health field. Do blacks prefer to be together? Do blacks prefer to be served or treated by blacks? Do

blacks prefer to have separate clinics with all-black personnel? Cornely also indicates that of all groups in our society, the poor black woman may be the most perceptive of life's realities. She knows that an integrated facility is better than an all-black one because, all too often, she and her children have been victims of oppression in public hospitals and clinics. She knows that when it is all-black, the physical facility tends to become obsolete and may even be condemned; personnel and supplies are in short supply and black providers are paid less than whites.

Besides the black American, other ethnic groups also experience similar difficulties regarding client-therapist relationships. Contemporary opinions hold that the American melting pot did not melt. Rather, American immigrants all have tended to identify with their ethnic origins by retaining their culture. By largely rejecting integration into a single group, Americans apparently have decided upon separate cultures, rather than blending as a unit into a common mold and one culture. For this reason, researchers stress the importance of knowing and understanding different cultures.

Bell and Zellman (1976), emphasize that, in working with ethnic groups, it is important to understand the differences that often exist within local communities. For example, among American Indians there are hundreds of tribes and a number of major tribal divisions. The extent to which tribal differences give rise to political and other differences is not clearly understood by white therapists. Mexican Americans also exhibit many historical and phenotypical differences among themselves. Of special significance are differences in residence and citizenship status.

Moreover, among black Americans there are many differences in social class politics and other factors which affect, or interfere with, unified community strategies for social action. These social and culture characteristics within the ethnic group population of an area must be understood if public programs are to be designed properly.

Bell and Zellman (1976), further indicate that factors which seem most important in affecting the use of services to elderly persons of minority groups are (1) differences in socioeconomic status; (2) culture factors; (3) differences in eligibility for services; (4) communication and language barriers; and (5) differences in physical and financial access.

In further research, Bell and Zellman particularly speak to the issue of communication and language barriers among the elderly members of the Asian and Mexican American communities. They indicate that there are many who are unable to understand and/or communicate in English. As a result of the communication and language barrier, many individuals may be unaware of the many services that exist. Fear of difficulties in communication may cause persons who cannot find a service provider within their community to forego such services altogether. This especially would be the case if fears of ethnic prejudice compound the embarrassment regarding the language difficulty. These researchers also pointed out that language barriers are often blamed for failures of service delivery which have more deep-seated causes.

Unlike a number of researchers, Bell and Zellman offer some suggestions for positive change regarding the majority provider and the minority client

issue. They indicate that a way to reduce cultural conflict between client and provider is to increase the availability of persons from the ethnic group who have professional training in medical and social service fields.

In a very enlightening study done by researchers in the California State Department of Education, Division of Vocational Education, Bureau of Occupational and Adult Education, the relationship between a white therapist and a black client is dealt with extensively.

These researchers are quick to point out, for example, that the characteristics of clients (such as their racial or ethnic groups, their birth places and their education) influence not only the problems for which they need help, but affect their ability to utilize social serivce agencies.

Particular reference is made regarding some black Americans who are uneducated and who are discriminated against because of race and consequently are unable to compete for skilled jobs. Moreover, their life of poverty affects their spirit and morale, all creating certain problems for which they may seek help.

If the social worker is white and the black client has been accustomed to hostile treatment by whites, especially in social service agencies, a good rapport is difficult to develop. Moreover, the black client's suspicion may lead him to doubt the sincerity of the friendship, advice or counsel, which the white therapist offers, no matter how unprejudiced the white therapist may be.

It is important, also, for white therapists and social service workers to recognize that the first reactions of black clients sometimes are based on what the therapist symbolizes, rather than what he or she is. The white therapist must, by his concern, willingness to help, and skill, help clients to overcome such resistance. At the same time, however, it is important for the therapist to be tolerant when black clients are angry or unfriendly to social service workers or therapists. The clients may expect that the white therapist will treat them as others have treated them in the past. The way individuals respond to others is based on their past experience, and many black clients have had more than their share of bitter experiences.

One of the more crucial points emphasized by the California researchers is that the white therapist must strive for empathy with black clients. Therapists should try to put themselves in their clients' place. Therapists should not feel sorry for them but rather try to understand what it would feel like to be in their shoes. No one can tell exactly how someone else feels but it is important to try to understand. The therapist must not let the way he or she feels get in the way of learning how the client feels about his problem.

Another important point made by these researchers is that the first person to see the client represents the agency and affects the client's view of the agency from that point on; therefore, the first contact must convey an interest in the client and his or her problem.

This interest should be accompanied by a calm but by no means uncaring manner, with an air of assurance which will give the client a feeling that things can be worked out and that there is no need for him to panic.

Moreover, in working with clients, especially black clients, it is important to remember that no problem or person is routine. Every problem is unique and has its own little twist.

Verbal and non-verbal forms of communication, words with "different" meanings, use of jargon, and listening are additional factors mentioned. It is easy to forget that the same words have different meanings for people of different backgrounds. Consider the different meanings which the phrase "lower class" has for social workers or therapists and the clients. To the professional, it has a particular factual meaning; it refers to persons with low income and limited education. To others, especially those who find themselves referred to as "lower class," it may suggest or imply inferiority, poor moral standards and inadequacy.

Sometimes misunderstanding is caused not by what is said but by what is not said. Inner feelings or attitudes often show in looks, gestures or tone of voice. This so-called body language is a form of non-verbal communication and people are extremely sensitive to the non-verbal or unspoken forms of communication.

If a therapist finds that he/she is having trouble getting through to people, it may be that he/she is sending out hidden messages, indicating anger, unfriendliness, a patronizing attitude. The people the therapist is trying to reach might be responding to these inner feelings rather than to his words. This especially may be the case in the white therapist-black client relationship.

The California group also indicates that the first step in becoming an effective listener is to relax. By letting the client talk, the worker gets an idea of what should be asked and also how to phrase the questions so that the client can understand them. It is also recommended that the clients speak freely at first. Usually the client will answer any questions that are asked.

Regarding the use of jargon, the researchers emphasize that it is important for the therapist to try to understand the meaning of the clients' language; however, the therapist should not use it himself unless he/she feels comfortable using it. This is particularly important in the white therapist-black client relationship.

Equally important to these California researchers is "response to clients." They indicate that feedback to what the client has said is crucial to understanding the problem.

The therapist may not like some of the behavior of some of his/her clients. However, the therapist can like the client or be interested in helping the client without approving his actions. If a client feels that he cannot tell a therapist what he actually feels without being criticized, the therapist will not be able to help him. Moveover, if a therapist is critical, he/she may stifle the clients' communication. Yet, it is vital to understand that the following is most important:

1. Clients release of pent-up feelings. That is, the clients should be encouraged to express their true feelings.

2. Asking questions.

3. Probing or prying - asking questions in order to get additional facts that are needed.

Researchers at the California State Department of Education also discuss the very important issue of "culture." These researchers indicate that cultural pluralism in America essentially involves the retention of separate ethnic, geographic, and racial identities. Moreover, they contend that America must be committed to a mixture of separate cultures as a significant value in our traditional way of life. Most importantly, they emphasize that a philosophical commitment to our stated constitutional and legislative ideals is not sufficient. Such a commitment in theory necessarily must be accompanied by an ever-greater commitment in practice lest our hallowed creed of "liberty and justice for all" should become only a hollow sham.

It is instructive to note, then, that there is no real unity within the diversity which our many cultural and ethnic groups represent. Instead, minorities still excluded from the mainstream American society are striving to establish an identification and a feeling of pride in their own heritage. Simultaneously, they are becoming increasingly more insistent on full-scale participation on equal terms in the normal affairs of American life.

Having a realistic perception of the concept of culture is vital, according to the California researchers. In their report they indicated that culture refers to the man-made environment. It is his skills, tools, folkways, and customs. Culture can refer to a group of people, a nation, or a community.

The things or objects particular to a certain group are its material culture. Ideas, beliefs, and attitudes incorporate nonmaterial culture. Value systems may be a nonmaterial element. Even the behavior pattern of certain people can be considered as a cultural nonmaterial difference.

The need for social approval is present to some extent in all human beings and man seeks social approval from those he comes in contact with, according to these researchers. However, one must remember that different cultures exhibit different social motives because people in different cultures learn different values in relation to their local society. One's tone of voice, or even his choice of words, may be influenced culturally. For instance, when an American worker might say, "Be good!", the French worker might say, "Be wise!", the Scandinavian says, "Be friendly!", and the Apache Indian says, "No, that is not the Apache way." As can be seen, each culture has its own way of influencing an individual's behavior. It is important to remember, therefore, that people have different values. Public servants and therapists need to acquire appropriate factual information about people of different cultures. They must realize the dignity, worth and basic rights of all people.

Cultural development, then, is not dependent upon race. It is the total way of life of any society. Culture is the sum of all experiences shared by individuals within a group. Moreover, cultures are not static; they grow and change. As they change, they affect man and society. The rate of travel today helps to foster cultural change. Cross-cultural experiences, therefore, may lead to cooperation, competition, or conflict. If each group is cooperating, usually society has fewer problems.

A recent effort addressed the issue of minorities specifically in the developmental disability service delivery system. The New Dimensions in Community Service, Inc., was funded by a grant from the Office of Human Development, Developmental Disability Office in 1977 to assess the quality and quantity of minority participation in the developmental disability movement. Minority parents and consumers were surveyed and raised the following concerns:

1. The developmental disabilities service delivery systems' apparent inability to render services in a comprehensive manner to the family as a unit. Participants stated that they were expected to devote their entire time to the child who is developmentally disabled. Social workers come into the home and do not see that the minority family often has other survival needs in addition to getting services for their disabled child.

   Parents are expected to attend meetings when no supportive services (i.e., babysitting or transportation) are made available. Agencies fail to realize that families suffer an emotional crisis with the birth of a disabled child. They need help in accepting this and in dealing with their own self-image as a parent.

2. The inability of agencies to reach out into minority communities and inform them about services. Most parents reported that they stumbled upon services, often hearing about a service from another parent or after "knocking on various agency doors." Many report being improperly referred or placed on long waiting lists.

3. The inability of many physicians to diagnose a child's problem and fully explain his/her potential for development in a way which is realistic yet not unnecessarily pessimistic. Parents reported incidences of being told to "put the child in an institution," or "leave him in the hospital." Parents also reported that some physicians act as if minority families lack the knowledge to understand their child's condition. Thus, physicians either don't tell them or say "he/she will grow out of it."

4. The lack of informational materials which are understandable and also available in non-English languages.

5. Parents also stated that in some instances they felt professionals gave their children an extremely poor prognosis for development because they were minorities.

6. The inflexibility of eligibility requirements, specifically those relating to income. Many single parent families reported an inability to pay for the cost of services in private institutions. They stated that income guidelines do not consider the problems faced by single parents who have other responsibilities.

7. The inability of agencies to focus on the similarities between inaccessibility of services to minority populations and discrimination, resulting in agencies dismissing the special concerns of minorities, claiming they are the "same as those of the majority."

8. The insensitivity of non-minority staff to the cultural differences of each of the minority populations. Consequently, parents stated, staff assumes what is true for the Spanish-speaking is true for the Asian or Black, or they assume all Indians are alike in their beliefs and ceremonial practices.

9. The inability of agencies to recognize, understand and handle parental mistrust. Related to this is the insensitivity parents feel is displayed by some agency receptionists. These are often the first persons the parents hear from and if they are turned off at this point, they (parents) will never call back.

10. The isolation of minorities in rural areas and the greater discrimination often suffered in these areas by minorities.

11. The failure of agencies to involve minorities in decision-making and planning in a meaningful manner, and further, to involve minority service providers in these activities.

12. The burden is placed on the parent to become involved while it should be placed on the agency to make that involvement meaningful.

13. The need for more agencies to recognize parents as a resource for reaching out to other parents who are afraid or ashamed to admit they have a disabled child.

14. The need for many agencies to recognize the value of providing parents the opportunity to have time for themselves away from their disabled child.

15. The need for current service providers to recognize that they cannot be all things to all populations and that in the interest of getting services to minority populations, each minority group might have to plan, design and implement its own service system.

16. The "game playing" agencies undergo when they say they can't find a "qualified minority person" to hire.

17. The value judgment many professionals make equating parent/consumer non-involvement in meetings to mean a lack of concern for their (parents) child's development. Parents reported that staff assume the parent is uninterested or is a bad parent if he/she doesn't attend meetings.

18. The need for service providers to understand the role of religious and cultural beliefs as they influence the parents use or non-use of services. Parents reported that some agencies don't understand these factors. The reality, parents report, is that many families whether minority or not, have similar beliefs, and further, that the general public has all kinds of myths about the disabled.

19. The lack of continuity in care given minority families who must use public health clinics. Parents reported that they often see a different doctor each time they visit the clinic and consequently, feel as if

they (parents) are just another patient. Parents report they resent being pushed from one doctor to another.

20. The need for staff (particularly in the outreach area) who are reflective of the racial, ethnic, and socio-economic class of those being served. The need for agencies to train current staff to be more sensitive to and understanding of minority client's needs.

CHAPTER III

PROCEDURE

The purpose of this section is to describe: (1) the procedure used in selecting the sample; (2) the procedure used in constructing the instrument; and (3) the procedure used in collection and coding of data.

Selection of Sample

The sample consists of minority individuals (Blacks, Native Americans, Hispanic, and Asians) diagnosed as having one or more of the developmental disabilities and who dropped out of the service delivery system during the 1976 calendar year or the 1976-77 school year in the State of Wisconsin.

Agencies, organizations, and schools identified as serving the above mentioned populations initially were contacted by means of a letter explaining the purpose of the study and requesting their assistance in identifying and contacting minority survey respondents who dropped out of the delivery system. Moreover, emphasis on the insurance of confidentiality of all information provided by them and the respondents identified by them was mentioned (see Appendix A.) In addition, individuals in these agencies, organizations, and schools were requested to make the initial contact with the client and to obtain his/her written consent to participate in the study (see Appendix A.)

If the agency, organization, or school agreed to participate in the study and if they identified individuals who had dropped out of the service

delivery system, the agencies, organizations or schools were sent copies of a letter explaining the purpose of the study (see Appendix B), copies of a request form (see Appendix B), and self-addressed envelopes with a stamp. They were requested to forward the letter, the request form, and the self-addressed envelope to the individuals they had identified. If the individual agreed to participate in the study, he/she returned the signed release form to the researcher's office. The researcher in turn forwarded to him/her a questionnaire requesting that he/she complete it and return it by a certain date.

Some agencies, organizations and schools were requested to mail the questionnaire along with the request form, the letter explaining the purpose of the project and the self-addressed envelope with stamp to the respondents. This was done because of the delay in identifying the respondents and/or because the agency, organization, or school felt most comfortable in contacting the respondents in this manner to maintain confidentiality.

The agencies and organizations that worked closely with the 51.42 Boards were sent a list of clients who had separated from the delivery system and who were identified by the following characteristics: client number, age, sex, heritage, and disability. These individuals were separated from the delivery system during the 1976 calendar year.

It is instructive to know that the client numbers were retrieved from the Master Record Tape in the Interim Information System in the Division of Community Services. Likewise, in order to identify those clients (admitted to the system during the 1976 calendar year) dropping out of the delivery

system served by the Department of Social Services a similar process was used; that is, a list of clients identified by client number, sex, heritage, and disability of clients was utilized. The Department of Social Services was requested to check their files to determine if any of these individuals had separated from their program. The abovementioned list of client numbers was retrieved from the Social Service Information System (SSIS). There was no way to determine if the clients had separated from the delivery system without direct contact with the Social Service Department.

Construction of Instrument

The instrument for this study was constructed by utilizing work done by other researchers, by utilizing input from professional staff in the DD system, and by interviewing developmentally disabled clients who were no longer in the DD system. Questions 14, 15, 26, 27, 30, 34, and 35 were revised from a questionnaire done by the Public Awareness Project. The background information section of the questionnaire, developed by this author, consisted of questions seeking information related to age, marital status, educational level, income, and race. The remaining questions in the instrument were developed by this author with assistance from the DD staff, DD providers, and individuals with developmental disabilities who were no longer receiving services in the delivery system.

Pretest

The pretest questionnaire (see Appendix C) was administered to minority individuals with developmental disabilities who had dropped out of the

service delivery system. Of the 22 who received the questionnaire, 14 returned the questionnaire, which is a response rate of 63 percent.

Initially, the pretest questionnaire contained 38 items. Responses from the 14 respondents in the pretest dictated changes in the questionnaire (see Appendix D). Moreover, as result of input from DD staff members and clients who had dropped out of the delivery system, questions 5, 6, 7, and 41 through 48 were added.

The pretest questionnaire and a letter indicating the purpose of the study, as well as a request for prompt return of the questionnaire, were mailed to individuals who were no longer receiving services in the delivery system. They were to return the questionnaire by May 1, 1978. A follow-up letter was mailed out to individuals who had not returned the questionnaire by May 5, 1978.

It is most important to mention that the pretest questionnaire was not the same as the one administered to individuals in correctional institutions identified as having one or more of the developmental disabilities (see Appendix E). The researchers in the Division of Corrections felt that this second questionnaire would best identify the needs of persons in correctional institutions.

The Collection of Data

When the questionnaire was completed by the client, it was returned in the self-addressed envelope provided by the researcher. If the client had

problems completing the questionnaire, he/she contacted the researcher by letter or phone indicating that they needed help to complete the questionnaire and requesting a face-to-face interview. If questionnaires returned in the mail were not completed, the researcher contacted the client, requesting an interview to complete the questionnaire.

Coding of Data

The data was punched into four 80-column cards for statistical analysis at the University of Wisconsin Survey Research Laboratory.

Summary

An instrument was developed to obtain data relevant to why minorities with developmental disabilities drop out of the service delivery system in the State of Wisconsin. The questionnaire was pretested by sending it to 22 individuals identified as dropping out of the service delivery system. Fourteen respondents returned the questionnaire and suggested revisions, and changes were made in the instrument based upon their request.

The revised questionnaire was sent to agencies, organizations, and schools (who forwarded the questionnaire to the individuals or to the person responsible for the developmentally disabled individual), and individuals with developmental disabilities who agreed to participate in the survey. Sixty-four questionnaires were returned, which represents a 12 percent return response

from agencies, organizations, and schools, and 18 questionnaires from correctional institutions, which represents a 100 percent return response.

TABLE I

Questionnaire Response

Percent Rounded

	N	%
Questionnaires returned - Left no forwarding address	136	26
Clients refused to participate	299	57
Questionnaires returned completed	82	16
Questionnaires returned incomplete	8	1
TOTAL	525	100%

CHAPTER IV

FINDINGS

The results in Table 2 present data relevant to demographic characteristics of the population used in this study. As indicated in the table, 58 percent of the population were males and 42 percent were females. Likewise, 74 percent of the respondents were Black Americans and 17 percent were Native Americans. In addition, Spanish Surname individuals comprised 6 percent of the population and Asian Americans made up 3 percent of the sample. Moreover, as reflected in this Table, 67 percent of the respondents were diagnosed as having mental retardation, 23 percent had epilepsy, 8 percent had cerebral palsy, and 2 percent had autism. Individuals between the ages of 22 and 33 comprised 42 percent of the population in this study. Furthermore, 52 percent of the population indicated that they had a mild form of their disability, 30 percent indicated a moderate form of disability, 12 percent listed their disability as severe, and 6 percent said their disability was profound.

Table 3 presents data indicating the distribution of income categories of respondents in this study. As shown, 47 percent of respondents have an income of less than $1,000.00, 34 percent of respondents have incomes between $1,000 and $2,999. The remaining 19 percent of respondents have incomes between $3,000 and $5,999.

The number of miles respondents have to travel to receive services is shown in Table 4. Eighty-four percent of the respondents are within fifteen miles of services; 6 percent respondents, 16 to 25 miles; 5 percent between 26 to 35 miles. Three percent of respondents are more than 56 miles away from services they should receive.

Related to the number of miles from services is the geographical area in which respondents live. In this regard, Table 5 presents data indicating the type of demographic area that respondents live in. As perhaps expected, 75 percent of respondents are from "urban" areas; 23 percent, from "rural" areas, 3 percent, "suburban" areas.

Table 6 shows data on employment status of respondents. Significantly, 59 percent of respondents indicated that they were unemployed. Another 17 percent of respondents were students, while 11 percent said they participated in sheltered workshops. Important to note is that 5 percent of respondents were employed full-time and 5 percent of respondents listed themselves as "homemakers." Three percent of the respondents indicated that they were employed part-time.

The distribution of responses indicating the number of additional family members with a developmental disability correlated by race is presented in Table 7. For Black respondents, 55 percent indicated that there were no additional family members with a developmental disability, while another 30 percent said that there was one other individual in their family with a disability. Additionally, eight percent said there were two other disabled family members and 4 percent said that there were four or more individuals in the family with a devleopmental disability. Seventy-three percent of Native Americans indicated that there were no other members in the family with a disability, while 27 percent indicated that there was one additional individual in their family with a disability.

TABLE 2

Demographic Characteristics of Study Population (N=64)

Variable	N	%
Sex		
Male	37	58
Female	27	42
Age		
Birth to 3 years old	--	
3 1/2-5 years	2	3
5 1/2-18 years old	17	27
19-21 years old	11	17
22-33 years old	27	42
34-44 years old	4	6
45-55 years old	2	3
56-older	1	2
Race		
Asian	2	3
Black	47	74
Native American	11	17
Spanish Surname	4	6
Marital Status		
Never Married	55	86
Married	5	8
Divorced	3	4
Widowed	1	2
Disability		
Mental Retardation	43	67
Cerebral Palsy	5	8
Epilepsy	15	23
Autism	1	2
Degree of Disability		
Mild	33	52
Moderate	19	30
Severe	8	12
Profound	4	6

TABLE 3

Distribution of Income of Individuals with Developmental Disabilities

	Percent Rounded	
	N	%
Income		
Less than $1,000.00	30	47
$1,000.00- 2,999.00	22	34
3,000.00- 5,999.00	12	19
Total	64	100%

TABLE 4

Distribution of the Number of Miles Individuals With Developmental Disabilities live From Services

	Percent Rounded	
	N	%
Miles From Service		
Within 15 miles	54	84
16-25 miles	4	6
26-35 miles	3	5
36-45 miles	1	2
46-55 miles	-	-
more than 56	2	3
Total	64	100%

TABLE 5

Distribution of Geographical Area of Individuals With Developmental Disabilities

	Percent Rounded	
	N	%
Geographical Area		
Urban	48	75
Rural	14	22
Suburban	2	3

TABLE 6

Distribution of Employment Status of Individuals With Developmental Disabilities

	Percent Rounded	
	N	%
Employment Status		
Full-Time	3	5
Part-Time	2	3
Homemaker	3	5
Sheltered Workshop	7	11
Student	11	17
Unemployed	38	59

TABLE 7

Distribution of Responses Indicating the Number of Additional Persons in the Nuclear Family with a Disability by Race

Percent Rounded

Race	None		1		2		3		4 or more		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
Asian	2	100	-	-	-	-	-	-	-	-	2	100
Black	26	55	14	30	4	8	1	2	2	4	47	100
Native American	8	73	3	27	-	-	-	-	-	-	11	100
Spanish	3	75	1	25	-	-	-	-	-	-	4	100
Total	39	61	18	28	4	6	1	2	2	3	64	100

Distribution of responses on the needs or problems of the person with a developmental disability is presented in Table 8. As shown in this table, 41 percent of the respondents indicated that they did not have babysitting, transportation and other special services. Likewise, 42 percent of the respondents indicated that "sometimes" they had these services, while 17 percent indicated that they "often" had these services.

Regarding whether or not respondents understood their disability, 6 percent indicated that they never understood their disability, whereas 31 percent indicated that they "often" understood their disability. Sixty-three percent of respondents indicated that they "sometimes" understood their disability.

A question on finding informational material that is understandable is also presented in Table 8. Fifty-five percent of respondents indicated that "sometimes" they found such materials, while 23 percent indicated they "never" found such materials and 22 percent indicated they "often" find such materials.

Concerning communication problems, Table 8 shows that 20 percent of respondents said that there is "never" a communication problem in understanding the staff. On the other hand, 22 percent of the respondents indicated that "often" there is a communication problem in understanding the staff. Fifty-eight percent of respondents, however, revealed that "sometimes" there is a communication problem in understanding the staff. Finally in this table, the issue of whether the agency's hours are in keeping with the respondents' needs is shown. Forty-two percent indicated that the agency

"often" kept hours that would cater to their needs, whereas 11 percent indicated that the agency "never" kept hours that would cater to their needs. The middle position was given by 47 percent of the respondents who indicated that "sometimes" agencies kept hours that would cater to their needs.

TABLE 8

Distribution of Responses on the Needs or Problems of the Individual with a Developmental Disability or the Person Responsible for the Developmentally Disabled Person

Expressed Needs or Problems	Sometimes		Often		Never	
	N	%	N	%	N	%
Do you have babysitting, transportation, etc. available?	27	42	11	17	26	41
Do you understand the developmental disability?	40	63	20	31	4	6
Have you been able to find informational material that is understandable?	35	55	14	22	15	23
Is there a communication problem in understanding the staff?	37	58	14	22	13	20
Are the agency hours in keeping with your needs?	30	47	27	42	7	11

Likewise, 22 percent indicated that staff are "never" helpful in informing them of services, whereas 13 percent indicated that "often" staff members are helpful in informing them of services.

Table 9 presents data indicating how individuals with developmental disabilities feel about developmental disabilities agencies staff members. Regarding whether the staff understood their needs, 61 percent of respondents indicated that "sometimes" staff understood their needs. Additionally, 28 percent of this population indicated that the staff "often" understood their needs, whereas 11 percent indicated that the staff "never" understood their needs.

Responses to the question "are you receiving the help you need from DD staff members" is also presented in Table 9. The data shows that 28 percent indicate that they "never" receive help from staff members, while 27 percent indicate that they "often" receive help from staff members. More significantly, 45 percent indicate that they "sometimes" receive help from DD staff members.

Regarding the issue of interest of staff members in meeting the needs of respondents, 55 percent indicate that "sometimes" staff members are interested in meeting their needs, while 12 percent say staff "never" are interested in meeting their needs. In a related question concerning the ease of discussing their problems with staff members, 55 percent of respondents reported that "sometimes" they are comfortable in discussing their problems with staff members, while 9 percent said they were "never" comfortable in discussing their problems and 38 percent said "often" they are comfortable in discussing their problems with staff members.

Most interestingly, this table shows to what extent staff members are helpful in informing respondents about services. As indicated, 58 percent said that "sometimes" staff members are helpful in informing them of services. Likewise, 22 percent indicated that staff are "never" helpful in informing them of services, whereas 13 percent indicated that "often" staff members are helpful in informing them of services.

In reference to missed appointments by respondents, 57 percent of this population said that "sometimes" staff members think that they are uninterested when they miss appointments. Also 26 percent indicate that staff members "never" think that they are uninterested when they miss an appointment and 17 percent indicate that "often" staff members think that they are uninterested when they miss an appointment.

Regarding the sensitivity and understanding of staff members as reflected in this table, 58 percent of respondents indicated that "sometimes" staff members should be more sensitive and understanding of their needs, while another 33 percent of respondents said staff members "often" should be more sensitive and understanding of respondents' needs. Also, 9 percent of respondents indicated that staff members "never" should be more sensitive and understanding of respondents needs.

TABLE 9

Distribution of Responses on How Individuals with Developmental Disabilities Feel About the DD Staff

Expressed Feeling Concerning Staff	Sometimes N	Sometimes %	Often N	Often %	Never N	Never %
Does the staff understand your needs?	39	61	18	28	7	11
Is the staff interested in meeting your needs?	35	55	21	33	8	12
Are you receiving the help you need from the staff?	29	45	17	27	18	28
Are you comfortable discussing your problems with the staff?	34	53	24	38	6	9
Are you expected to devote most of your time to the individual with a developmental disability?	31	48	21	33	12	19
Is the staff helpful in informing you about services?	37	58	13	20	14	22
Does the staff think you are uninterested when you miss an appointment?	36	57	11	17	17	26
Should the staff be more sensitive to and understanding of your needs?	37	58	21	33	6	9

The variable of disability is considered in relation to a number of other variables in Tables 10 through 15. To begin with, Table 10 outlines how minority individuals with developmental disabilities pay for services received. Clearly as reflected in Table 10 mental retardation is the predominant disability. Forty percent of those with mental retardation paid for services received by means Supplementary Security Income (SSI), and 26 percent paid by other means. When the disabilities were viewed totally, 36 percent paid for services by means of Social Security Income (SSI), and 14 percent by means of medical assistance.

Data presented in Table 11 shows how the respondents, according to their disability, would evaluate the staff. For people with mental retardation, 43 or 67 percent indicated that the staff was insensitive whereas 16 or 36 percent indicated that the staff was sensitive. These same approximate percentages hold when viewing the entire sample.

Table 12 shows the respondents' reply to the question: "How would the individual with the disability rate the quality of services received?" As illustrated, 46 percent of respondents indicated that the services were poorly organized, while 32 percent indicated that the services were adequately organized, and 22 percent indicated that the services were well organized.

Table 13 shows the distribution of responses to the question: "Has the individual with the disability ever been refused help by an agency?" In viewing this table, 34 percent of the respondents replied yes when questioned concerning the refusal of assistance from agencies and 66 percent of the respondents

replied no when questioned concerning the refusal of assistance from agencies. More specifically, 35 percent of those who were mentally retarded were turned down by agencies, while 25 percent of those with cerebral palsy and 27 percent of those with epilepsy were refused assistance from agencies.

In Table 14, when asked, "If the individual with the disability is no longer receiving help and why?", 17 percent of the respondent indicated that they no longer received help because they moved; 15 percent stated that they completed the program, and 17 percent indicated that the program was no longer available to them. Significantly, 50 percent indicated that their program was not meeting their needs.

The data presented in Table 15 are essentially responses to the question "Does the individual with the disability need help in the following areas?" Ten areas were listed for the respondents to choose from. As illustrated in the table, four different disabilities are correlated with the following ten areas: transportation, protective service, sheltered employment, recreation, education, training, counseling, evaluation, diagnosis, and treatment.

In reference to respondents who were mentally retarded, the table shows that 35 percent of these individuals needed help for transportation, while 30 percent needed counseling and education. Also, 23 percent of this same group needed sheltered employment, training, and treatment. Nineteen percent of the mentally retarded needed evaluation and 12 percent needed protective services and recreation.

For those respondents with epilepsy, the data show that 53 percent of this group indicated a need for "treatment", while 47 percent of this same group express a need for "counseling". Moreover, 36 percent of those with epilepsy expressed a need for "transportation" and another 20 percent of respondents indicated a need for protective services, sheltered employment, training, evaluation, and diagnosis. The scarcity of data does not allow for much analysis as reflected in the table regarding individuals with cerebral palsy and autism.

TABLE 10

Distribution of Responses on Indicating How Individuals Pay for Services Received by Disability

Percent Rounded

Disability	Family Income		Social Security Income (SSI)		Medical Assistance		Other		Total	
	N	%	N	%	N	%	N	%	N	%
Mental Retardation	7	16	17	40	8	18	11	26	43	100
Cerebral Palsy	1	20	2	40	--	--	2	40	5	100
Epilepsy	7	47	4	27	1	7	3	20	15	100
Autism	--	--	--	--	--	--	1	100	1	100
Total	15	23	23	36	9	14	17	27	64	100

TABLE 11

Distribution of Responses Indicating How Individuals With Disability Would Evaluate the Staff

	Percent Rounded					
	Insensitive		Sensitive		Total	
Disability	N	%	N	%	N	%
Mental Retardation	27	63	16	37	43	100
Cerebral Palsy	3	60	2	40	5	100
Epilepsy	8	57	6	43	14	100
Autism	1	100	--	--	1	100
Total	39	62	24	38	63	100

TABLE 12

Distribution of Responses Indicating the Quality of Services Received by Disability

Percent Rounded

Disability	Poorly Organized		Adequately Organized		Well Organized		Total	
	N	%	N	%	N	%	N	%
Mental Retardation	23	58	8	17	11	25	42	100
Cerebral Palsy	2	40	2	40	1	20	5	100
Epilepsy	4	27	9	60	2	13	15	100
Autism	—	--	1	100	--	--	1	100
Total	29	46	20	32	14	22	63	100

TABLE 13

Distribution of Responses Indicating Refusal of Assistance from Agencies

Percent Rounded

Disability	Yes		No	
	N	%	N	%
Mental Retardation	16	38	26	62
Cerebral Palsy	1	25	3	75
Epilepsy	4	27	11	73
Autism	--	--	1	100
Total	21	34	41	66

TABLE 14

Distribution of Responses Indicating Reasons Why Individuals With Disabilities Are No Longer Receiving Assistance

Percent Rounded

Area of Disability	Moved		Completed Program		Not Meeting Needs		Program No Longer Available		Total	
	N	%	N	%	N	%	N	%	N	%
Mental Retardation	4	14	4	14	15	54	5	18	28	100
Cerebral Palsy	1	50	1	50	--	--	--	--	2	100
Epilepsy	2	20	1	10	5	50	2	20	10	100
Autism	--	--	--	--	--	--	--	--	--	--
Total	7	17	6	15	20	50	7	17	40	100

TABLE 15

Distribution of Responses of Individuals Receiving Assistance According to Disability in the Following Areas

Percent Rounded

Area of Disability	Transportation				Protective Services				Sheltered Employment				Recreation				Education			
	Rec'd. Assist.		Did Not Receive Assist.		Rec'd. Assist.		Did Not Receive Assist.		Rec'd. Assist.		Did Not Receive Assist.		Rec'd. Assist.		Did Not Receive Assist.		Rec'd. Assist.		Did Not Receive Assist.	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Mental Retardation	15	35	28	65	5	12	38	88	10	23	33	76	5	12	38	88	13	30	30	70
Cerebral Palsy	1	20	4	80	--	--	5	100	--	--	5	100	--	--	5	100	4	80	1	20
Epilepsy	5	36	9	64	3	20	12	80	3	20	12	80	1	7	14	93	6	40	9	60
Autism	1	100	--	--	--	--	1	100	--	--	1	100	--	--	1	100	1	100	--	--
Total	22	35	41	65	8	12	56	88	13	20	51	80	6	9	58	91	24	37	40	63

(Continued)

TABLE 15

(Continued)

Distribution of Responses of Individuals Receiving Assistance According to Disability in the Following Areas

Area of Disability	Training				Counseling				Evaluation				Diagnosis				Treatment			
	Rec'd. Assist.		Did Not Receive Assist.		Rec'd. Assist.		Did Not Receive Assist.		Rec'd. Assist.		Did Not Receive Assist.		Rec'd. Assist.		Did Not Receive Assist.		Rec'd. Assist.		Did Not Receive Assist.	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Mental Retardation	10	23	33	77	13	30	30	70	8	19	35	81	6	14	37	86	10	23	33	77
Cerebral Palsy	1	20	4	80	2	40	3	60	1	20	4	80	1	20	4	80	1	20	4	80
Epilepsy	3	20	12	80	7	47	8	53	3	20	12	80	3	20	12	80	8	53	7	47
Autism	1	100	--	--	--	--	1	100	1	100	--	--	1	100	--	--	1	100	--	--
Total	15	23	49	77	22	34	42	66	13	20	51	80	11	17	53	83	20	31	44	69

The distribution of responses indicating what happened after the initial contact with an agency is presented in table 16. As shown, 55 percent of respondents indicated that after their initial contact with an agency, they were placed on a waiting list, while 27 percent were assigned to a counselor as well as receiving information about services after their initial contact with an agency. Additionally, 17 percent of respondents were referred to other agencies and 5 percent of their respondents were refused the services of the agencies after their initial contact with an agency.

The length of time respondents had to wait before receiving services is presented in table 17. In general, 55 percent of respondents dealt with this issue. Significantly, 16 percent of respondents had to wait between three and four weeks before receiving services and another 16 percent of respondents indicated that they were still on the "waiting" list to receive services. Additionally, 11 percent indicated that it took less than two weeks to receive the services, whereas another 11 percent of respondents said it took between 5 and 8 weeks before they received services.

Continuing in the same vein, table 18 presents data indicating the distribution of responses on the frequency of desired follow-up as requested by respondents. Thirty percent of respondents desired follow-up at least "once a month".

Other respondents desired follow-up in the following fashion: twice a month (20 percent), less than once a month (14 percent), more than once a month (11 percent), and three times a month (9 percent). Also, for six percent of respondents a response was not ascertained and for eight percent of respondents "inappropriate" responses were given.

TABLE 16

Distribution of Responses Indicating What Happened After the Initial Contact With an Agency

	Percent Rounded	
Initial Contacts	N	%
Assigned to a Counselor	17	27
Placed on a Waiting List	35	55
Referred to Another Agency	11	17
Given Information About Services	17	27
Refused Help	3	5
Other	3	5

TABLE 17

Distribution of Responses Indicating the Length of Time Respondents Had to Wait Before Receiving Services

	Percent Rounded	
Time	N	%
Less than 2 weeks	7	11
3-4 weeks	10	16
5-8 weeks	7	11
9-12 weeks	2	3
13-16 weeks	1	1
Still on waiting list	10	16
Not Ascertained	2	3
Inappropriate	25	39
Total	64	100

TABLE 18

Distribution of Responses Indicating the Frequency of Follow-up Desired

	Percent Rounded	
Frequency of Follow-up	N	%
Less than a month	9	14
Once a month	19	30
Twice a month	13	20
Three times a month	6	9
More than once a week	7	11
Never	1	2
Not Ascertain	4	6
Inappropriate	5	8
Total	64	100

Table 19 shows the distribution of responses by age indicating how individuals with developmental disabilities would evaluate the staff working with them as being sensitive or insensitive. Specifically, the data indicate that 62 percent of all age groups view the staff that is working with them as "insensitive", while only 38 percent of the respondents felt that the staff working with them were "insensitive." Moreover, 63 percent of 22-33 age groups, the largest group represented, viewed the staff that were working with them as being "insensitive." In addition, 75 percent of the 5½ to 18 years age group and 55 percent of the 19 to 21 age group also viewed the staff that were working with them as "insensitive."

TABLE 19

Distribution of Responses on How the Individual With the Disability Would Evaluate the Staff According to Age

Age	Percent Rounded					
	Insensitive		Sensitive		Total	
	N	%	N	%	N	%
3 1/2-5	2	100	--	--	2	100
5 1/2-18	12	75	4	25	16	100
19-21	6	55	5	45	11	100
22-33	17	63	10	37	27	100
34-44	--	--	4	100	4	100
Over 44	2	67	1	33	3	100
Total	39	62	24	38	63	100

Tables 20 and 21 present data concerning the quality of service (table 21) and an evaluation of staff (table 20) as correlated by sex. The distribution of responses indicating how respondents would evaluate the staff working with them as being insensitive or sensitive is shown in table 21.

Sixty-four percent of male respondents indicated that staff working with them were "insensitive," whereas 36 percent of male respondents indicated that staff working with them were "sensitive." On the other hand, 59 percent of female respondents indicated that staff working with them were "insensitive," while 41 percent of female respondents indicated that staff working with them were "sensitive."

The distribution of responses indicating the quality of services received as correlated by sex is presented in table 21. Significantly, 46 percent of all respondents indicated that the services received were "poorly organized" as compared to 22 percent of all respondents who thought that the quality of services were "well organized." Also, 32 percent of all respondents indicated that the services were "adequately organized." Importantly, 50 percent of male respondents thought services received were "poorly organized," 36 percent thought services received were "adequately organized" and 14 percent thought services received were "well organized." Conversely, 41 percent of female respondents felt that services received were "poorly organized", 26 percent of the female respondents thought services received were "adequately organized" and 33 percent of female respondents felt services were "well organized."

TABLE 20

Distribution of Responses on How the Individual With a Disability Would Evaluate the Staff by Sex

Sex	Insensitive		Sensitive		Total	
	N	%	N	%	N	%
Male	23	64	13	36	36	100
Female	16	59	11	41	27	100
Total	39	62	24	38	63	100

TABLE 21

Distribution of Responses on the Quality of Services Received by Sex

Percent Rounded

Sex	Poorly Organized		Adequately Organized		Well Organized		Total	
	N	%	N	%	N	%	N	%
Male	18	50	13	36	5	14	36	100
Female	11	41	7	26	9	33	27	100
Total	29	46	20	32	14	22	63	100

The distribution of responses indicating the area of help the individual with developmental disability received is presented in table 22. As indicated, in general, respondents did not receive a great deal of assistance in the listed areas. More specifically, the highest percentage of assistance received was 38 percent in the area of "education." Conversely, the highest percentage of non-assistance was 91 percent in the area of "recreation." The next highest percentage of assistance received in decreasing order were transportation (36%), counseling (34%), treatment (31%), training (23%), sheltered employment and evaluation (20%), diagnosis (17%), protective services (13%) and recreation (9%). Likewise, the next highest percentage of non-assistance in decreasing order were protective services (87%), diagnosis (83%), sheltered employment and evaluation (80%), training (77%), treatment (69%), counseling (66%), transportation (65%) and education (62%).

Table 23 pertains to the responses of individuals with developmental disabilities who encountered problems in the areas of: transportation, protective services, sheltered employment, recreation, education, training, counseling, evaluation, diagnosis, and treatment. The data reveals that in general, respondents experienced fewer problems in the aforementioned areas. To illustrate, the highest percentages indicating non-response because of inappropriate actions encountered in the listed areas are (in decreasing order): protective services (91%), evaluation (89%), counseling and diagnosis (87%), treatment (84%), recreation (81%), sheltered employment (80%), training (75%), education and transportation (69%). On the other hand, the areas with the highest percentages of problem encountered in decreasing order are: transportation and education (31%),

training (25%), sheltered employment (20%), recreation (19%), treatment (16%), counseling and diagnosis (13%), evaluation (11%), and protective services (9%).

Tables 24 and 25 present data indicating whether or not individuals with developmental disabilities refused help in the listed areas and whether or not individuals with developmental disabilities ever have been terminated from services in the listed areas. The distribution of responses indicating the areas some respondents refused services is shown in table 24. Recreation (8%) and counseling (6%) had the highest percentage of help refused by respondents. Other areas in decreasing order are sheltered employment, treatment, education, and training (each 5%); transportation (3%); and protective services and diagnosis (2%).

In table 25, the distribution of responses indicating whether the individual with developmental disabilities had been terminated from one of the listed areas is given. In general, the data show that the majority of respondents were not terminated from the following areas in decreasing order: sheltered employment (15%), education (11%), protective services, transportation, recreation and treatment (9%), training and counseling (8%), evaluation (4%) and diagnosis (3%).

The data presented in table 26 shows the distribution of responses by race indicating how individuals with developmental disabilities would evaluate the staff working with them as being sensitive or insensitive. Significantly, 66 percent of Black respondents saw the individuals working with them as being "insensitive" and 60 percent of Native Americans had a similar perception of the staff working with them; that is, an insensitive staff. Likewise, 50 percent of Spanish respondents saw the staff working with them as being "insensitive." Equally significant, the data shows that 100 percent of Asian respondents saw the staff members working with them as being "sensitive."

In reference to race as correlated with relationship to staff, the data presented in table 27 reflects a general view that respondents might be receptive to staff. Regarding the staff's appreciation of the value and life styles of respondents, fifty percent of blacks indicated that staff didn't appreciate their values and life styles, whereas another 50 percent of blacks said that staff was appreciative of the values and lifestyles of blacks. For Native Americans, 30% had a "yes" vote, whereas 70 percent had a "no" vote. To the issue of whether or not the staff could be improved to serve respondents better, 69 percent of blacks indicate "yes", while 73 percent of Native Americans indicate the affirmative. When respondents were asked the question "Have you been informed of your legal rights?," 64 percent of respondents indicated that they have not been informed of their legal rights. For the same question, when presented to Native Americans, 45 percent indicate that they have not been informed of their legal rights.

Similar findings are found in table 28 regarding sex. Regarding staff's testing to recognize respondents' needs, 56 percent of males and 42 percent

of females indicated that staff did testing effectively to recognize their needs. In reference to staff's appreciation of the values and lifestyles of respondents, 51 percent of males felt that staff did not have an appreciation of their values and lifestyles, whereas 46 percent of females felt that staff did not appreciate their values and lifestyles. Concerning staff improvement to serve them better, 73 percent of males indicate that staff could improve to serve them better, as compared to 52 percent of females who held a similar view. Regarding being informed of their legal rights, 65 percent of the male respondents indicated that they had not been informed of their legal rights, whereas 52 percent of female respondents indicated that they had not been informed of their legal rights.

TABLE 22

Distribution of Responses on Help the Individual With Developmental Disability Received

Areas	Received Help Checked		Did Not Receive Help Not Checked	
	N	%	N	%
Transportation	23	36	41	64
Protective Services	8	13	56	87
Sheltered Employment	13	20	51	80
Recreation	6	9	58	91
Education	24	38	40	62
Training	15	23	49	77
Counseling	22	34	42	66
Evaluation	13	20	51	80

TABLE 23

Distribution of Responses on Problems Encountered

Areas	Problem Encountered Checked (Percent Rounded)		No Problem Encountered Not Checked (Percent Rounded)	
	N	%	N	%
Transportation	20	31	44	69
Protective Services	6	9	58	91
Sheltered Employment	13	20	51	80
Recreation	12	19	52	81
Education	20	31	44	69
Training	16	25	48	75
Counseling	8	13	56	87
Evaluation	7	11	57	89
Diagnosis	8	13	56	87
Treatment	10	16	54	84

TABLE 24

Distribution of Responses Indicating if Refused Help

Areas	Checked		Not Checked	
	Percent Rounded			
	N	%	N	%
Transportation	2	3	62	97
Protective Services	1	2	63	98
Sheltered Employment	3	5	61	95
Recreation	5	8	59	92
Education	3	5	61	95
Training	3	5	61	95
Counseling	4	6	60	94
Evaluation	-	-	64	100
Diagnosis	1	2	63	98
Treatment	3	5	61	95

TABLE 25

Distribution of Responses Indicating the Areas the Individual with Developmental Disabilities were Terminated

	Yes		No	
Area	N	%	N	%
Transportation	6	9	58	91
Protective Services	6	9	58	91
Sheltered Employment	10	15	54	85
Recreation	6	9	58	91
Education	7	11	57	89
Training	5	8	59	92
Counseling	5	8	59	92
Evaluation	3	4	61	96
Diagnosis	2	3	62	97
Treatment	6	9	58	91

TABLE 26

Distribution of Responses Indicating How Individuals With a Disability Would Evaluate the Staff by Racial Status

Percent Rounded

	Insensitive		Sensitive		Total	
	N	%	N	%	N	%
Racial Status						
Asian	--	--	2	100	2	100
Black	31	66	16	34	47	100
Native American	6	60	4	40	10	100
Spanish	2	50	2	50	4	100
Total	39	62	24	38	63	100

TABLE 27

Distribution of Responses Indicating Respondent's Relationship and Perception of Staff Members According to Race

Percent Rounded

Statements	Asian		Black		Native American		Spanish	
	Yes	No	Yes	No	Yes	No	Yes	No
Do you think the staff tested you to recognize your needs?	100%	--	50%	50%	55%	45%	100%	--
Do you think the staff has an appreciation of your values and lifestyles?	50%	50%	53%	47%	30%	70%	75%	25%
Could the staff be improved to serve you better?	---	100%	68%	32%	73%	27%	25%	75%
Have you had personal clashes with the staff?	---	100%	19%	81%	46%	54%	25%	75%
Do you think you were tested differently?	---	100%	26%	74%	18%	82%	67%	33%

TABLE 28

Distribution of Responses Indicating Respondent's Relationship and Perception of Staff Member According to Sex

Percent Rounded

Statements	Male		Female	
	Yes	No	Yes	No
Do you think the staff tested you to recognize your needs?	65%	35%	42%	58%
Do you think the staff has an appreciation of your values and life style?	49	51	54	46
Could the staff be improved to serve you better?	73	27	52	48
Have you had personal clashes with staff?	22	78	26	74
Do you think you were tested differently?	31	69	19	81
Have you been informed of your legal rights?	35	65	48	52

The distribution of responses indicating how individuals with developmental disabilities find out about the service delivery system is presented in table 29. As shown in the table, 39 percent of respondents found out about services through their social worker. Likewise, another 33 percent of respondents were informed of services from their families or friends. In addition, 16 percent of respondents were informed through their DVR counselor and 13 percent of respondents were informed of services by their doctor or nurse. Interestingly, 8 percent of respondents found about services through their community agencies such as Community Action Council, Urban League, and Neighborhood Centers, whereas 11 percent of respondents indicated that they did not know how they found out about services.

TABLE 29

Distribution of Responses Indicating How Individuals with Developmental Disabilities Find out about Services Received

	Percent Rounded	
	N	%
Newspaper	2	3
Television	3	4
Doctor or Nurse	8	13
Library	2	3
Family or Friend	21	33
Community Agencies (CAC, Urban League, Neighborhood Centers, etc)	5	8
Radio	1	2
Brochures, Newsletter, pamphlet	1	2
Social Worker	25	39
Another person with a disability	3	4
DVR Counselor	10	16
Churches	-	-
Don't Know	7	11

*Note: Respondents were allowed to check as many as apply.

During September 1978, visits were made to Ethan Allen School, a juvenile correctional institution, and the Wisconsin State Reformatory, a maximum security adult correctional institution, to conduct interviews with a small sample of male residents with developmental disabilities. Fifteen mentally retarded residents and three residents with epilepsy were interviewed.

Questions asked during the interviews dealt primarily with the types of services which are being and have been provided and the overall satisfaction with those services. The goal of the project was to determine whether persons with developmental disabilities are dropping out of the service delivery system and, if so, why.

Persons convicted of felonies or adjudicated delinquent and subsequently committed to state correctional institutions are generally unhappy with their plight and, therefore, express dissatisfaction with their treatment, housing, food and programs. A secondary goal of the project was to determine if developmentally disabled residents also expressed their displeasure with their treatment even though specialized staff and programs have been organized to meet their unique needs.

Results of the interviews with the sample of 18 developmentally disabled residents is presented in the following discussion and in tables 30 through 43. The reader is cautioned against using this information for budgeting or policy development. The number of residents interviewed is too small to make inferences about the total population.

Tables 30 and 31 present data indicating how a sample of surveyed individuals with developmental disabilities in correctional institutions rate the quality of services received. In Table 30, it can be seen that 56 percent of respondents (N=18) feel that services are poorly organized as compared to 16 percent of respondents who indicate that services are "well organized". Also, 28 percent of respondents said that services were "fairly organized."

In examining Table 31, responses indicate how individuals in correctional institutions rate the quality of services received as correlated with type of disability. Significantly, of respondents who were mentally retarded (N=15) 60 percent said that services were "poorly organized." Twenty-seven percent of the same group indicated that services were "fairly organized," whereas thirteen percent of the respondents said that services were "well organized." Moreover, the respondents who had epilepsy (N=3) were split evenly among the three levels of qualities of service.

The distribution of responses indicating how individuals in correctional institutions evaluated staff sensitivity as correlated by age is shown in Table 32. The results are consistent with earlier findings in that a large percentage (89%) of respondents found developmental disability staff members to be "insensitive," while 100 percent of the 19-21 age group (N=5) had a similar view.

Satisfaction with developmental disability staff members as viewed by individuals with developmental disabilities who are in correctional institutions is the subject matter of data presented in Tables 33 and 34. As shown in Table 33, the data reveals that 61 percent of respondents said

that "sometimes" staff members understand their needs. while 39 percent of respondents indicate that staff "never" understand their needs. Regarding the reception of the maximum amount of assistance from developmental disability staff members, 66 2/3 percent of respondents indicated that they "never" received all of the assistance they needed, whereas 33 1/3 percent of respondents said that "sometimes" they received all of the assistance they need. In addition, 61 percent of respondents indicated that they did not feel comfortable in discussing their problems with staff members, and 50 percent of respondents also said that they felt that staff members were not interested in meeting their needs.

A more in depth perspective of staff satisfaction as perceived by respondents is presented in Table 34. Specifically, the feelings of individuals who have either mental retardation or epilepsy are correlated with responses concerning respondent's feelings toward staff. Forty-seven percent of respondents who are mentally retarded (N=15) indicated that staff "never" understood their needs, while another 53 percent said that developmental disability staff "sometimes" understood their needs, while another 53 percent said that developmental disability staff "sometimes" understands their needs. Moreover, 73 percent of respondents indicated that they did not receive all of the help they needed. For both the mentally retarded and those with epilepsy (N=18), over 60 percent said that they felt uncomfortable in discussing their problems with devleopmental disability staff members. In addition, respondents indicated that there is a need for staff change or improvement. Those with epilepsy especially stressed that there is such a need.

TABLE 30

Distribution of Responses Indicating How Individuals in Correctional Institutions Rate the Quality of Services Received

Percent Rounded

Ratings	N	%
Poorly organized	10	56
Fairly organized	5	28
Well organized	3	16
Total	18	100

TABLE 31

Distribution of Responses Indicating How Individuals in Correctional Institutions Rate the Quality of Services Received by Disability

Percent Rounded

	Poorly Organized		Fairly Organized		Well Organized		Total	
Disability	N	%	N	%	N	%	N	%
Mental Retardation	9	60	4	27	2	13	15	100
Epilepsy	1	33 1/3	1	33 1/3	1	33 1/3	3	100
Total	10	55	5	28	3	17	18	100

TABLE 32

Distribution of Responses Indicating the Sensitivity of Staff by Age of Respondent

Percent Rounded

	Insensitive		Sensitive		Total	
Ages	N	%	N	%	N	%
16-18	10	91	1	9	11	100
19-21	5	100	-	-	5	100
22-33	1	50	1	50	2	100
Total	16	89	2	11	18	100

TABLE 33

Distribution of Responses on How Individuals With Developmental Disabilities Feel About the DD Staff

Expressed Feelings	Often		Sometimes		Never	
	N	%	N	%	N	%
Do you feel the staff understood your needs?	-	-	11	61	7	39
Do you feel the staff are interested in meeting your needs?	-	-	9	50	9	50
Are you receiving all of the help you need from the staff?	-	-	6	33 1/3	12	66 2/3
Do you feel comfortable discussing your problems with the staff?	2	11	5	28	11	61
Do you feel the staff is helpful in informing you about available services?	1	6	9	50	8	44
Do you feel staff need to be trained to be more sensitive and understanding?	7	38	10	55	1	6
Do you feel the staff have tested you to recognize your needs?	2	11	9	50	7	39
Do you feel staff has an adequate appreciation of your values and lifestyles?	2	11	8	44	8	44
Do you feel the staff could be improved or changed?	8	44	8	44	2	11
Do you feel you are tested differently?	9	50	6	33	3	17

TABLE 34

Distribution of Responses on How Individuals With Developmental Disabilities Feel About the DD Staff by Disability

	Mental Retardation						Epilepsy					
	Often		Sometimes		Never		Often		Sometimes		Never	
Expressed Feelings	N	%	N	%	N	%	N	%	N	%	N	%
Do you feel the staff understands your needs?	-	-	8	53	7	47	-	-	3	100	-	-
Do you feel the staff are interested in meeting your needs?	-	-	6	40	9	60	-	-	3	100	-	-
Are you receiving all of the help you need from the staff	-	-	4	27	11	73	-	-	2	66 2/3	1	33 1/2
Do you feel comfortable discussing your problems with the staff?	2	13	4	27	9	60	-	-	1	33 1/3	2	66 2/3
Do you feel the staff is helpful in informing you about available services?	-	-	9	60	6	40	1	33 1/3	-	-	2	66 2/3
Do you feel staff need to be trained to be more sensitive and understanding?	6	40	8	53	1	7	1	33 1/3	2	66 2/3	-	-
Do you feel the staff has tested you to recognize your needs?	1	6	7	47	7	47	1	33 1/3	2	66 2/3	-	-
Do you feel staff has an adequate appreciation of your values and lifestyles?	1	6	7	47	7	47	1	33 1/3	1	33 1/3	1	33 1/3
Do you feel the staff could be improved or changed?	2	13	6	40	7	47	1	33 1/3	2	66 2/3	-	-
Do you feel you were tested differently?	9	60	3	20	3	20	3	100	-	-	-	-

The distribution of responses indicating the type of disability of the resident is presented in Table 35. As shown, 15 of respondents were mentally retarded and three had epilepsy.

Data relevant to training programs is presented in Tables 36, 37, 38 and 39. In Table 36, 72 percent of respondents answered "no" when asked whether they were currently receiving training-related services in the correctional institutions. The 5 persons receiving training-related services were asked whether or not their needs were being met. Four of 5 replied "yes", as reported in Table 37. In reference to individuals receiving other training-related services since admission, 78 percent said "no", while 22 percent said "yes", as shown in Table 38. The respondents were asked if they felt they should be receiving training related services. Fifty-six percent said "no", while 44 percent said "yes".

Information regarding education programs is presented in Tables 40 through 43. In Table 40, responses to the question "Are you currently receiving education-related services in the institution?" are given. Clearly, 56 percent of respondents said "no", whereas 44 percent said "yes". Response to the question "Are these services meeting your needs?" is shown in Table 41. Interestingly, of the 8 receiving services, only 5 answered "yes" and 3 said "no". It may be instructive to note that 61 percent of the respondents answered "no" to the question regarding whether they received any other education-related services since admission. Regarding whether or not respondents felt that they should be receiving education-related services, 56 percent replied "no", whereas 44 percent said "yes".

TABLE 35

Distribution of Responses Indicating the Disability of the Individual

Percent Rounded

Disability	N	%
Mental Retardation	15	83
Cerebral Palsy	-	-
Epilepsy	3	17
Autism	-	-
Total	18	100

TABLE 36

Distribution of Responses Indicating if Respondents are Receiving Training-Related Services in the Institution

Percent Rounded

Response	N	%
Yes	5	28
No	13	72
Total	18	100

TABLE 37

Distribution of Responses Indicating if Training-Related Services are Meeting the Needs of Persons With DD in Correctional Institutions

Response	N	%
Yes	4	80
No	1	20

TABLE 38

Distribution of Responses Indicating if Respondents Have Received Other Training-Related Services Since Admission

Response	N	%
Yes	4	22
No	14	78

TABLE 39

Distribution of Responses Indicating If Individuals Feel They Should be Receiving Training-Related Services

Variable	N	%
Yes	8	44
No	10	56
Total	18	100

TABLE 40

Distribution of Responses Indicating if Respondents are Receiving Education-Related Services in the Institutions

Variable	N	%
Yes	8	44
No	10	56
Total	18	100

TABLE 41

Distribution of Responses Indicating if Education-Related Services are Meeting Their Needs

Variable	N	%
Yes	5	62
No	3	38

TABLE 42

Distribution of Responses Indicating if Respondents Have Received Other Education-Related Services Since Admission

Variable	N	%
Yes	11	61
No	7	39
Total	18	100

TABLE 43

Distribution of Responses Indicating if Individuals Feel They Should be Receiving Education-Related Services

Variables	N	%
Yes	8	44
No	10	56
Total	18	100

CHAPTER V

Discussion and Implications

Observers in numerous agencies and organizations have indicated that minority individuals enter the service delivery system but many of these individuals leave the system prematurely. Consequently, these individuals do not receive the maximum help needed. Keeping this in mind, the purpose of this study was to investigate why minority group members with developmental disabilities drop out of the service delivery system. The five objectives of the study were:

1. To determine if the individual with the developmental disability ever encountered any problems in the service delivery system.

2. To determine if the individual with the developmental disability was ever refused any help from the service delivery system.

3. To determine what help, if any, the individual with the developmental disability needs from the service delivery system.

4. To determine how the individual with the developmental disability finds out about the service delivery system.

5. To determine how the individual with a developmental disability feels about the DD staff.

It may be instructive to note that minority respondents do encounter problems in the delivery system as reflected by the data in this report. For example, eighty-three percent of respondents indicated that they had varying degrees

of problems with babysitting and transportation. Likewise, eighty percent of respondents said that there is a communication problem in understanding the staff that is working with them. Although there are varying degrees of difficulties regarding these problems, it must be stressed that there are problems encountered by minority individuals in the service delivery system.

Most interestingly, the problems that minority individuals encountered with developmental disability staff members are quite significant. Sixty-one percent of minority respondents indicated that "sometimes" staff members understood their needs, while eleven percent of respondents said that staff never understood their needs. This represents a total of 71 percent of respondents who revealed that there is a problem of staff members understanding "their" needs.

Akin to the issue of staff understanding individual needs is the issue of whether or not individuals feel comfortable in discussing their problems with staff members. In this regard, 62 percent of respondents indicate varying degrees of difficulties in discussing their problems with developmental disability staff members. It is not surprising, then, that 91 percent of those sampled indicated in varying degrees that developmental disability staff members should be more sensitive and understanding of minority client needs.

Not only is there a problem concerning the staff when viewing the issue generally, there is a problem when one views it in reference to each disability group, by sex, by age, and by race. To illustrate, individuals with the following disabilities evaluated developmental disability staff members as being "insensitive" according to these percentages: mental retardation

(63%),cerebral palsy (60%), epilepsy (57%) and autism (100%). With the exception of those with epilepsy, over sixty percent of minority individuals with the aforementioned disabilities view developmental disability staff members as being "insensitive." Moveover, 64 percent of male respondents found developmental disabilities staff members to be "insensitive" and 59 percent of female respondents said that developmental disabilities staff members were "insensitive." Furthermore, sixty-six percent of Black respondents found developmental disabilities staff members to be "insensitive", and sixty percent of Native Americans felt the same way. Also, fifty percent of Spanish respondents indicated that developmental disabilities staff members are "insensitive". In addition, at least fifty-five percent in all age groups indicated that developmental disabilities staff members were "insensitive".

As evidenced by the data, minority individuals with developmental disabilities who participated in this study encountered problems with the developmental disability staff individuals who were working with them. In reference to the first stated objective, the problem of staff "insensitivity" is a crucial one. An important consideration is that if staff is not able to relate effectively to clients, how effective is their work? Does this affect the individual to the extent that he/she may want to "drop out" of the system? Ultimately, is staff "insensitivity" a factor that leads to the drop-out of minority individuals in the developmental disability delivery system? The evidence in this study certainly suggests that this may be a possibility.

Regarding the second stated objective concerning the respondent's refusal of assistance from the service delivery system, the data show that 38 percent of respondents who are mentally retarded refused assistance

from agencies while 27 percent of those with epilepsy refused assistance and 25 percent of those with cerebral palsy refused help from agencies. It is interesting to note that the above percentages represent a little over 3 percent of the total respondents.

Perhaps related to the second objective (respondent's refusal of assistance) are matters pertaining to the length of time respondents had to wait before receiving assistance and what happened to a respondent after their initial contact with an agency as well as the respondent's desired "follow-up" activities. Regarding initial contacts, over fifty percent of respondents were put on a waiting list. Perhaps the respondents viewed this as an indication that something positive would happen for them. It is interesting to note that only 3% of respondents actually refused services after their initial contact with an agency. It also seems that respondents maintained a certain degree of patience since they were willing to "wait" for services.

In reference to the third objective regarding the kind of help or assistance individuals with developmental disabilities would need from the service delivery system, the data reveal that minority individuals received a minimal amount of assistance. An in depth look at Table 15 reveals that 65 percent of all respondents did not receive transportation. Likewise, 88 percent of respondents did not receive protective services, while 91 percent of respondents did not receive recreation. Additionally, 63 percent of clients did not receive education, 77 percent did not receive evaluation, 83 percent did not receive counseling, 80 percent did not receive treatment. Clearly, this information suggests that minority individuals with developmental disabilities who participated in this study need more assistance in the aforementioned areas. In particular, respondents seem to need more assistance

in the areas of protective services, sheltered employment, and recreation. In addition, more training, evaluation, and diagnosis should be utilized. Evidence also indicates that both males (50%) and females (41%) think that services are poorly organized.

Regarding the fourth objective of determining how individuals with a developmental disability find out about the services delivery system, it is evident that the individual's social worker and the individual's family and friends play an important role. Cleraly the data shows that minority respondents depended heavily on these individuals for assistance regarding finding services. It is because of this situation that the role of developmental disability staff members is so crucial. To say the least, a good rapport is imperative if realistic gains are to be made toward the development of the minority person who happens to have a developmental disability.

RECOMMENDATIONS

The following recommendations are made as a result of this study:

1. A follow-up study using the interview process should be done to include the service providers as well as the clients who are no longer receiving services in order to better assess why minority individuals drop out of the service delivery system.

2. Workshops should be planned for DD staff as well as DD minority clients in order to establish a better line of communication.

3. Ongoing minority sensitivity training programs should be considered as a part of the job requirement for staff persons working with DD individuals.

4. Workshops should be developed and provided for DD individuals or the persons responsible for the DD individual to provide them with information concerning their disability, their legal rights, available services, etc.

5. A study which focuses on the attitudes of staff working with people with DD would perhaps shed some light in the area of insensitivity.

6. Training and education programs for DD individuals should be developed with a definite future in mind rather than a here today-gone tomorrow adventure.

7. Follow-up should be provided for those who have dropped out of the program and for those on the waiting list.

8. A comparison study of minority DD individuals and majority DD individuals should be done to determine if problems may differ for the majority DD individual who cannot get needed services.

IMPLICATION OF THE STUDY

An obvious question that comes to mind is "what are the practical implications of this study?" One answer could be the early identification of problems that affect the minority individual as well as individuals working in the service delivery system. It is imperative that developmental disability staff members realize that they are involved in a two-way street. Often they may contribute to problems in their attempts to solve them. Moreover, developmental disability staff members must realize that the problem does not always lie with the developmentally disabled person. To take such a position would be to "blame the victim." Developmental disability staff members must be ready to say "I might be part of the problem." Assuming such a viewpoint is the first step toward realistically addressing the problem.

Early identification of problems could result in the positive development of minority individuals. In particular, by having a "sensitive" staff person who understands the needs of minority individuals would result in the increased awareness and self development of the individual. Moreover, a positive self image as well as increased motivation will most likely enable the minority individual to deal realistically with their disability. This in turn would aid the developmental disability staff member in further assisting the minority disabled individual.

CONCLUSION

The issue of why minorities with developmental disabilities abandon the service delivery system prematurely was the focus of this study. A review of literature regarding the dropout issue was made as well as a pilot study of minorities who dropped out of the service delivery system. As a result of the pilot study, a general study was made utilizing the following objectives:

1. To determine if the individual with the developmental disability ever encountered any problems in the service delivery system.

2. To determine if the individual with the developmental disability ever refused any help from the service delivery system.

3 To determine what help if any, the individual with the developmental disability needs from the service delivery system.

4. To determine how the individual with the developmental disability finds out about the service delivery system.

5. To determine how the individual with the developmental disability feels about the DD staff.

Results of this investigation indicated that developmental disability staff working with minority individuals with developmental disabilities were viewed as "insensitive". Moreover, minority clients were in need of services such as transportation and babysitting.

Recommendations were made concerning elimination of obstacles which may continue to impede progress for minority individuals.

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APPENDIX A

AGENCY INTRODUCTORY LETTER

State of Wisconsin \ DEPARTMENT OF HEALTH & SOCIAL SERVICES

DIVISION OF COMMUNITY SERVICES
1 WEST WILSON STREET
MADISON WISCONSIN 53702

April 25, 1978

Dear

The Council on Developmental Disabilities has funded a project to study why minority groups drop out of the delivery system. The study will consist of a statewide survey of individuals who are no longer receiving services in the delivery system. Therfore, we are requesting your help in identifying and contacting survey respondents who dropped out of the delivery system from among your client population. The racial groups that we are looking at are Blacks, Native Americans, Asians, and Spanish Surname. The disabilities that we are looking at are cerebral palsy, epilepsy, mental retardation, and autism.

The survey will be conducted by means of a mailed questionnaire or a face-to-face interview. The survey time is approximately 45 minutes and is scheduled to take place in May of 1978.

We will insure the confidentiality of all information provided by you and by the clients who are interviewed. The names of participating clients will not be used in any project reports. Survey responses will be aggregated so that no one will be able to determine what any particular individual has said. In addition, we are requesting that a third party such as your agency make the initial contact with the individual and obtain his/her written consent to participate in the study.

If you agree to assist us, we would like to work with you on some procedure for selecting clients who represent one of the disabilities and one of the four minority groups. We are only interested in those individuals who dropped out during the 1977 calendar year, the 1976-77 school year, and those individuals in the community seeking help but for some reason not receiving all of the help they need.

We would appreciate your prompt consideration of our request. While the survey is more than six weeks away, we will be doing some exploratory interviews with members of the four disability groups in Madison and Milwaukee. It would be extremely helpful if we could speak with some of your clients in this preliminary phase of our work.

We look forward to hearing from you. If you have any questions regarding our request, or the project as a whole, please feel free to contact me.

Sincerely

Ruth Murphy
Research Analyst

APPENDIX B

CLIENT INTRODUCTORY LETTER

CLIENT RELEASE FORM

State of Wisconsin \ DEPARTMENT OF HEALTH & SOCIAL SERVICES

DIVISION OF COMMUNITY SERVICES
1 WEST WILSON STREET
MADISON, WISCONSIN 53702

I have been hired by the Council on Developmental Disabilities to do a state survey needs assessment of minority persons with cerebral palsy, epilepsy, autism or mental retardation. We are interested in knowing the problems individuals with disabilities have encountered, if any; the help individuals with disabilities need, if any; the help individuals with disabilities have refused and why; and the way individuals with disabilities find out about the different types of services available to them.

I would like to ask you to participate in this survey needs assessment project. Your participation is very important. There will be no direct benefits from participating in this study; however, the results of the study may be useful in helping the general population in planning to meet the needs of minority persons with developmental disabilities.

The survey will take approximately 45 minutes to complete. For those individuals who might have problems with the written questionnaire, a face-to-face interview will be arranged. Any information obtained from you will remain confidential.

Your decision to participate in the survey will not affect the quantity or quality of care available to you.

Please fill out the enclosed slip if you agree to participate in the survey and mail it to us in the enclosed self-addressed stamped envelope by _____.

If you have further questions concerning the project, please contact me at (608) 266-6660.

Thank you in advance for your time and cooperation.

Sincerely

Ruth Murphy Research Analyst

Enclosures

I, _____, hereby agree to participate in the survey entitled An Assessment of Why Minority Groups With Developmental Disabilities Drop Out of the Service Delivery System. I understand the survey study is under the supervision of Ruth Murphy and that I will not receive any direct benefits from participating in this study. I understand that my decision to participate in the study will not affect the quantity or quality of care available to me and that information obtained from me will remain confidential. I also understand that the study is very important and the results of the study may be useful in helping the general population in planning to meet the needs of minority persons with developmental disabilities.

_____ _____

Signature Date

APPENDIX C

PRETEST

SURVEY

Directions: Please provide the requested information as accurately as possible by checking ( ) one response for each question unless otherwise instructed. All information will be treated confidentially.

1. Are you the parent, guardian, or the individual with the disability completing this survey?
   _____Yes
   _____No

   If yes, please indicate.
   _____Parent
   _____Guardian
   _____Individual with the disability

2. If no, indicate one of the following if applicable.
   _____Counselor
   _____Friend
   _____Teacher
   _____Nurse
   _____Other Please specify_____

3. How many persons are there in your family with developmental disabilities?
   _____One
   _____Two
   _____Three
   _____Four or more

4. How are you related to the individual who has a developmental disability?
   _____Mother _____Brother _____Daughter
   _____Father _____Son
   _____Sister
   _____Other Please specify_____

5. What is the sex of the individual with the developmental disability?
   _____Male
   _____Female

6. What is the racial status of the individual with the developmental disability?
   _____Black
   _____Native American
   _____Asian
   _____Spanish Surname
   _____Other Please specify_____

7. How old is the person with developmental disability?
   _____Birth to 3 years old
   _____3½ - 5 years old
   _____5½ - 18 years old
   _____19-21 years old
   _____22 years or older

8. What is the disability of the individual?
   _____Mental retardation
   _____Cerebral palsy
   _____Epilepsy
   _____Autism

9. What is the degree of the disability?
   _____Mild
   _____Moderate
   _____Severe
   _____Profound

10. Indicate the type of living arrangement of the individual with the disability?
   _____Independently (alone)
   _____With parents or relatives
   _____Group home (apartment living, residential treatment, residential community)
   _____Nursing home
   _____Foster parents
   _____Other Please specify_____

11. If the individual is living in a group home, nursing home, or with foster parents, do you feel that this type of living arrangement is meeting his/her needs?
   _____Yes
   _____No

12. If yes, please list the ways this type of living arrangement is meeting his/her needs.

13. If no, please list the ways this type of living arrangement is not meeting his/her needs.

14. What length of time has the individual with the disability been assigned to these arrangements?
   _____Permanently
   _____Temporary (respite, assessment only)
   _____Period of training

15. In what geographical area does the individual with the disability live.
   _____Urban
   _____Rural
   _____Suburban

16. Indicate the number of miles the individual with the disability lives from the services being received?
   _____Within 15 miles
   _____16-25 miles
   _____26-35 miles
   _____36-45 miles
   _____46-55 miles
   _____More than 56 miles

17. What is the last grade of school the individual with the disability completed?_____

18. What is the employment status of the individual with the disability?

_____Full-time
_____Part-time
_____Homemaker
_____Looking for work
_____Sheltered workshop
_____Student
_____Unemployed

19. What is the yearly income of the individual with the disability?

_____Less than $1,000.00
_____$1,000.00 - $2,999.00
_____$3,000.00 - $5,999.00
_____$6,000.00 - $7,999.00
_____$8,000.00 - $10,000.00
_____More than $10,000

20. Does the individual with the disability have any say about the services being received?

_____Yes
_____No

2. If yes, in what capacity is the individual with the disability able to express his/her concerns?

_____As a board member
_____As a staff member
_____As a member of legislature
_____As a volunteer
_____As a client
_____Other Please specify_____

22. If no, why doesn't the individual with the disability have any say about the services being received?

_____Not encouraged to comment
_____Don't know where or to whom to comment
_____Do not feel that comments are of value
_____Other Please specify_____

23. Would the individual with the disability like to voice his/her opinion concerning the services being received?

_____Yes
_____No

24. If yes, what are some of the concerns of the individual with the disability? Please specify.

25. If no, why not? Please specify.

26. How does the individual with the disability pay for services received?

_____Family income
_____Social Security Income SSI
_____Medical Assistance
_____Other Please specify._____

27. How would the individual with the disability rate the quality of services received?

_____Poorly organized
_____Adequately organized
_____Well Organized

28. How would the individual with the disability evaluate the staff working in schools, agencies or institutions where services are being received?
_____Insensitive to client needs
_____Sensitive to client needs

29. Has the individual with the disability had any problem receiving help in his/her community?
_____Yes Explain
_____No Explain

30. Is the individual with the disability receiving help in any of the following areas?
_____Transportation
_____Protective services
_____Sheltered employment
_____Recreation
_____Education
_____Training
_____Counseling
_____Evaluation
_____Diagnosis
_____Treatment

31. Has the individual with the disability ever encountered any problems in the following areas?
_____Transportation
_____Protective services
_____Sheltered employment
_____Recreation
_____Education
_____Training
_____Counseling
_____Evaluation
_____Diagnosis
_____Treatment

32. Has the individual with the disability ever refused any help in any of the following areas. If yes, indicate with a check. Please explain.
_____Transportation
_____Protective services
_____Recreation
_____Education
_____Training
_____Counseling
_____Evaluation
_____Diagnosis
_____Treatment

33. Has the individual with the disability ever been refused help by an agency?
_____Yes
_____No

If yes, what reason was given.

34. Does the individual with the disability need help in any of the following areas?
_____Transportation
_____Protective services
_____Recreation
_____Education
_____Training
_____Counseling
_____Evaluation
_____Diagnosis
_____Treatment

35. If the individual with the disability is no longer receiving help in the above areas, why not?
_____Moved
_____Completed program
_____Not meeting needs
_____Program no longer available

36. How did the individual with the disability find out about the services received?
_____Newspaper
_____Radio
_____Television
_____Brochures, newsletter, pamphlet
_____Doctor or Nurse
_____Social Worker
_____Library
_____Another person with a disability
_____Family or friend
_____DVR Counselor
_____Community Agencies (CAC, Urban League, Neighborhood centers, etc.)
_____Churches

37. What happened after your initial contact?
_____assigned to a counselor
_____placed on a waiting list
_____referred to another agency
_____given information about the services offered
_____refused help
_____Other Please specify_____

38. How often do you like follow-up?
_____less than once a month
_____twice a month
_____three times a month
_____more than once a week
_____Never

39. Has the individual with the disability ever been placed on a waiting list?
_____Yes
_____No

40. If yes, how long has the individual with the disability had to wait before receiving services?
_____Two weeks or less
_____3-4 weeks
_____5-8 weeks
_____9-12 weeks
_____More than twelve weeks

41. While on the waiting list has the individual with the disability ever been contacted to see if they were receiving any other services?
_____Yes
_____No

42. Additional comments

REACTION TO QUESTIONNAIRE

1. Time to complete survey:

   _____minutes

   Comments:

2. Were the directions clear?

   _____Yes
   _____No

   (If No, please specify and recommend needed change.)

3. Were the questions or statements clear?

   _____Yes

   _____No

   (If No, please specify the questions or comments.)

4. Was the questionnaire well organized?

   _____Yes
   _____No

   (If No, please give suggestions.)

5. Other Comments:

APPENDIX D

FINAL QUESTIONNAIRE

SURVEY

Directions: Please carefully read each of the following otems in the left of the page. To the right of each item, please indicate your response with a check ( ).

1. Which of the following are you completing this survey?

   Individual with disability_____
   Parent or guardian of individual with disability_____
   Counselor of individual with disability_____
   Teacher of individual with disability_____
   Friend of individual with disability_____
   Other, please specify_____

2. What is the disability of the individual?

   Mental retardation_____
   Cerebral palsy_____
   Epilepsy_____
   Autism_____

3. What is the degree of the disability?

   Mild_____
   Moderate_____
   Severe_____
   Profound_____

4. Indicate the type of living arrangement of the individual with the disability.

   Independent (alone)_____
   With parents or relatives_____
   Group home (apartment living, residential treatment, residential community)_____
   Nursing home_____
   Foster parents_____
   Other_____

5. If the individual is living in a group home, nursing home, or with foster parents, do you feel that this type of living arrangement is meeting his/her needs?

   Yes_____
   No_____

6. If no, please list the ways this type of living arrangement is not meeting his/her needs.

7. What length of time has the individual with the disability been assigned to these arrangements?

Permanent_____
Temporary (respite, assessment only)_____
Period of training_____

8. In what geographical area does the individual with the disability live?

Urban_____
Rural_____
Suburban_____

9. Indicate the number of miles the individual with the disability lives from the services being received.

Within 15 miles_____
16-25 miles_____
26-35 miles_____
36-45 miles_____ 46-55 miles_____
More than 56 miles_____

10. What is the last grade of school the individual with the disability completed?_____

11. What is the employment status of the individual with the disability?

Full-time_____ Sheltered workshop_____
Part-time_____ Student_____
Homemaker_____ Unemployed_____
Looking for work_____

12. What is the yearly income of the individual with the disability?

Less than $1,000.00_____
$1,000.00-$2,999.00_____
$3,000.00-$5,999.00_____
$6,000.00-$7,999.00_____
$8,000.00-$10,000.00_____
More than $10,000.00_____

13. Does the individual with the disability have any say about the services being received?

Yes_____ No_____

14. If yes, in what capacity is the individual with the disability able to express his/her concerns?

As a board member_____
As a staff member_____
As a member of legislature_____
As a volunteer_____
As a client_____
Other_____ Please specify_____

15. If no, why doesn't the individual with the disability have any say about the services being received?

Not encouraged to comment_____
Don't know where or to whom to comment_____
Do not feel that comments are of value_____
Other_____ Please specify_____

16. Would the individual with the disability like to voice his/her opinion concerning the services being received?

Yes_____ No_____

17. If yes, what are some of the concerns of the individual with the disability?

18. If no, why not? Please specify.

19. If the individual with the disability cannot talk or know his/her needs, would the persons responsible for the individual with the developmental disability like to voice an opinion concerning the decisions being made?

Yes_____ No_____

20. If yes, what are your concerns? Please specify.

21. If no, why not? Please specify.

22. How does the individual with the disability pay for services received?

Family income_____
Supplemental Security Income SSI_____
Medical Assistance_____
Other_____ Please specify_____

23. How would the individual with the disability rate the quality of services received?

Poorly organized_____
Adequately organized_____
Well organized_____

24. How would the individual with the disability evaluate the staff working in schools, agencies or institutions where services are being received?

Insensitive to client needs_____
Sensitive to client needs_____

25. Has the individual with the disability had any problem receiving help in his/her community?

Yes_____ Explain
No_____ Explain

26. Is the individual with the disability receiving help in the following areas? If yes, indicate with a check ( ). Check ( ) as many that apply.

Transportation_____
Protective services_____
Sheltered employment_____
Recreation_____
Education_____
Training_____
Counseling_____
Evaluation_____
Diagnosis_____
Treatment_____

27. Has the individual with the disability ever encountered any problems in the following areas? If yes, indicate with a check ( ). Check ( ) as many that apply.

Transportation_____
Protective services_____
Sheltered employment_____
Recreation_____
Education_____
Training_____
Counseling_____
Evaluation_____
Diagnosis_____
Treatment_____

28. Has the individual with the disability ever refused any help in the following areas? If yes, indicate with a check ( ). Please explain.

Transportation_____
Protective services_____
Sheltered employment_____
Recreation_____
Education_____
Training_____
Counseling_____
Evaluation_____
Diagnosis_____
Treatment_____

29. Has the individual with the disability ever been refused help by an agency?

Yes_____ No_____

30. Does the individual with the disability need help in the following areas? If yes, indicate with a check. Check ( ) as many that apply.

Transportation_____
Protective services_____
Sheltered employment_____
Recreation_____
Education_____
Training_____
Counseling_____
Evaluation_____
Diagnosis_____
Treatment_____

31. If the individual with the disability is no longer receiving help in the above areas, why not?

Moved_____
Completed program_____
Not meeting needs_____
Program no longer available_____

32. Has the individual with the disability ever been terminated from the following areas? If yes, indicate with a check. ( ).

Transportation_____
Protective services_____
Sheltered employment_____
Recreation_____
Education_____
Training_____
Counseling_____
Evaluation_____
Diagnosis_____
Treatment_____

33. If so, what reason(s) was (were) given?

Disruptive, unmanageable behavior_____
Completed program_____
No funds available_____
Other_____ Please specify_____

34. How did the individual with the disability find out about the services received?

Newspaper_____
Television_____
Doctor or Nurse_____
Library_____
Family or friend_____
Community Agencies (CAC, Urban League, Neighborhood Centers, etc._____
Radio_____
Brochures, newsletter, pamphlet_____
Social Worker_____
Another person working with a disability_____
DVR Counselor_____
Churches_____
Don't know_____

35. What happened after your initial contact?

Assigned to a counselor_____
Placed on a waiting list_____
Referred to another agency_____
Given information about the services offered_____
Refused help_____
Other_____ Please explain_____

36. If you were placed on a waiting list, how long did you have to wait before receiving services?

Less than 2 weeks_____
3-4 weeks_____
5-8 weeks_____
9-12 weeks_____
13-16 or more weeks_____
Still on waiting list_____

37. How often do you like follow-up?

Less than once a month_____
Once a month_____
Twice a month_____
Three times a month_____
More than once a week_____
Never_____

38. Has the individual with the disability ever been placed on a waiting list?

Yes_____ No_____

39. While on the waiting list has the individual with the disability ever been contacted to see if they were receiving any other services?

Yes_____ No_____

PLEASE CHECK ( ) ONE RESPONSE FOR EACH ITEM

40. How does the individual with DD or the person responsible for the DD individual feel about the DD staff.

	Sometimes	Often	Never
Do you feel that the staff working with Developmental disabilities understand your needs?	_____	_____	_____
Do you feel that the staff working with developmental disabilities are interested in meeting your needs?	_____	_____	_____

Do you feel that the staff working with developmental disabilities are interested in meeting your needs? _____ _____ _____

Do you feel that you are receiving all of the help that you need from the DD staff? _____ _____ _____

Do you feel comfortable discussing your problems with the developmental disabilities staff? _____ _____ _____

Do you feel that the developmental disabilities staff expect you to devote most of your time to the individual with the disability? _____ _____ _____

Do you feel that the developmental disability staff is helpful in informing you about services available to you? _____ _____ _____

Do you feel that DD staff think that you are uninterested when you miss an appointment? _____ _____ _____

Do you feel the need for DD agencies to train staff to be more sensitive to and understand your needs? _____ _____ _____

41 Indicate the needs or problems of the individual with DD or the person responsible for the DD individual. Please check ( ) one response for each item.

Do you have babysitting, transportation, etc., available to you for attending meetings? _____ _____ _____

Do you feel that you fully understand your DD problems or the problems of the individual with a developmental disability? _____ _____ _____

Have you been able to find informative materials about the disability that are understandable? _____ _____ _____

Is there a communication problem in understanding the staff person when he/she explains the developmental disability to you?

Do you feel that the agency hours are in keeping with your needs? _____ _____ _____

PLEASE CHECK ( ) ONE RESPONSE FOR EACH ITEM.

	Yes	No
42. Do you think that agency staff have tested you in a manner which recongizes your individual needs? If not, what problems have you had? Please explain. Use back of page for additional comments.	_____	_____

43. Do you think that the staff has an adequate appreciation of your values and life-style? If not, what problems are there? Please explain. Use back of page for comments. _____ _____

44. Do you think the staff could be improved or changed to serve you better? If yes, please explain. How might these changes be accomplished? Use back of page. _____ _____

45. Have you had any personal clashes with DD staff? If yes, explain. Use back of page for comments. _____ _____

46. Do you feel that you are tested differently by staff from other persons receiving services? If yes, please explain. Use back of page for comments. _____ _____

47. Have you been informed of your legal rights by the staff? _____ _____

48. How many other persons are there in your family with cerebral palsy, mental retardation, epilepsy or autism?

One_____
Two_____
Three_____
Four or more_____
None_____

49. What is the sex of the individual with the developmental disability?

Male_____ Female_____

50. What is the recial status of the individual with the developmental disability?

Asian_____
Black_____
Native American_____
Spanish Surname_____
Other, please specify_____

51. How old is the individual with the developmental disability?

Birth to 3 years old_____
3 ½ - 5 years old_____
5 ½ - 18 years old_____
19-21 years old_____
22-33 years old_____
34-44 years old_____
45-55 years old_____

52. What is the marital status of the individual with the developmental disability?

Never married_____
Married_____
Divorced_____
Widowed_____

53. Additional Comments:

APPENDIX E

CORRECTIONS QUESTIONNAIRE

SURVEY

Purpose: The purpose of this questionnaire is to collect information on the needs of persons with cerebral palsy, epilepsy, autism or mental retardation in Correctional Institutions. There will be no direct benefit from participating in this study; however, the results of the study may be useful in planning to meet the needs of persons with developmental disabilities.

Directions: Please carefully read each of the following questions on the page. Indicate your response with a (X) next to your response.

1. Which of the following developmental disabilities do you have?

   Mental retardation_____
   Cerebral palsy _____
   Epilepsy _____
   Autism _____

2. What is the degree of the disability?

   Mild _____
   Moderate _____
   Severe _____
   Profound _____

3. Education Programs

   A. Are you currently receiving education-related services in the institution?

      Yes _____
      No _____

      If yes, please specify how long you have received these services.

   B. Are these services meeting your needs?

      Yes _____
      No _____

      If no, why not?

   C. Since admission have you received any other education-related services?

      Yes _____
      No _____

If yes, please specify program.

Name of program	How many months did you receive this service?	Reason you are no longer receiving services.
1._____	_____	_____
2._____	_____	_____
3._____	_____	_____
4._____	_____	_____

D. Do you feel you should be receiving education-related services but are not?

Yes _____
No _____

If yes, why are you not receiving services?

4. Training Programs

A. Are you currently receiving training-related services in the institution?

Yes _____
No _____

If, yes please specify how long you have received these services.

B. Are these services meeting your needs?

Yes _____
No _____

If no, why not?

C. Since admission, have you received any other training-related services?

Yes _____
No _____

If yes, please specify:

Name of program	How many months did you receive service?	Reason for no longer receiving services.
1._____	_____	_____
2._____	_____	_____
3._____	_____	_____
4._____	_____	_____

D. Do you feel you should be receiving training-related services but are not?

Yes _____
No _____

If yes, why are you not receiving services?

5. Counseling programs (Social Work - Psychiatric)

A. Are you currently receiving counseling-related services in the institution?

Yes _____
No _____

If yes, please specify how long you have received these services.

B. Are these services meeting your needs?

Yes _____
No _____

If no, why not?

C. Since admission have you received any other counseling-related services?

Yes _____
No _____

If yes, please specify program.

Name of Program	How many months did you receive this service?	Reason for no longer receiving service.
1._____	_____	_____
2._____	_____	_____
3._____	_____	_____
4._____	_____	_____

D. Do you feel you should be receiving counseling-related services but are not?

Yes _____
No _____

If yes, why are you not receiving services.

7. Work-related Programs

A. Are you currently receiving work-related services in the institution?

Yes _____
No _____

If yes, please specify how long you have received these services.

B. Are these services meeting your needs?

Yes _____
No _____

If no, why not?

C. Since admission have you received any other work-related services?

Yes _____
No _____

Name of Program	How many months did you receive this service?	Reason for no longer receiving service.
1. _____	_____	_____
2. _____	_____	_____
3. _____	_____	_____
4. _____	_____	_____

D. Do you feel you should be receiving work-related services but are not?

Yes _____
No _____

If yes, why are you not receiving services?

8. Medical / Dental Programs

A. Are you currently receiving medical or dental-related services in the institution?

Yes _____
No _____

If yes, please specify how long you have received these services?

B. Are these services meeting your needs?

Yes _____
No _____

If no, why not?

C. Since admission have you received any other medical / dental-related service?

Yes _____
No _____

If yes, please specify.

Name of Program	How many months did you receive this service?	Reason for no longer receiving services.
1._____	_____	_____
2._____	_____	_____
3._____	_____	_____
4._____	_____	_____

D. Do you feel you should be receiving medical and/or dental services but are not?

Yes _____
No _____

If yes, why are you not receiving services?

9. Have you ever been terminated from any program in the institution?

Yes _____
No _____

If yes, what reason(s) was (were) given?

10. To your knowledge are there any staff at the institution who are assigned to work with developmental disabilities?

Yes _____
No _____

PLEASE CHECK (X) ONE RESPONSE FOR EACH ITEM

11. How do you feel about the staff working in the institution?

	Sometimes	Often	Never
Do you feel that the staff working with developmental disabilities understand your needs?	_____	_____	_____
Do you feel that the staff working with developmental disabilities are interested in meeting your needs?	_____	_____	_____
Do you feel that you are receiving all of the help that you need from the developmental disabilities staff?	_____	_____	_____
Do you feel comfortable discussing your problems with the developmental disabilities staff?	_____	_____	_____
Do you feel that the developmental disabilities staff is helpful in informing you about services available to you?	_____	_____	_____
Do you feel that the developmental disabilities staff think that you are uninterested when you miss an appointment?	_____	_____	_____
Do you feel the need for developmental disability agencies to train staff to be more sensitive to and understand your needs?	_____	_____	_____
Do you feel that agency staff have tested you in a manner which recognizes your individual needs? If not, what problems have you had? Please specify. Use back of page for additional comments.	_____	_____	_____
Do you feel that the staff has an adequate appreciation of your values and life-style? If not, what problems are there? Please specify. Use back of page for comments.	_____	_____	_____
Do you feel the staff could be improved or changed to serve you better? If yes, please explain. How might these changes be accomplished? Use back of page.	_____	_____	_____
Do you feel that you are tested differently by staff from other persons receiving services? If yes, please specify. Use back of page for comments.	_____	_____	_____

12. Have you had any personal clashes with the developmental disability staff?

Yes _____
No _____

If yes, please specify.

13. Have you been informed of your legal rights by the staff.

Yes _____
No _____

14. Do you have any say about the services being received in the institution?

Yes _____
No _____

15. If yes, in what capacity are you able to express your concerns?

As a client_____
Other_____Please specify_____

16. If no, why don't you have any say about the services being received?

Not encouraged to comment._____
Don't know where or to whom to comment_____
Do not feel that comments are of value_____
Other_____Please specify_____

17. Would you like to voice your opinion concerning the services being received?

Yes _____
No _____

18. If yes, what are some of your concerns?

19. If no, why not? Please specify.

20. How would you rate the quality of services received at the institution?

21. How would you evaluate the staff working in the institution where services are being received?

22. Have you had any problems receiving help in the institution?

Yes _____
No _____

If yes, please specify.

23. How many other persons are there in your family (mother, father, sister or brother) with cerebral palsy, mental retardation, epilepsy or autism?

None _____
One _____
Two _____
Three _____
Four or more _____

24. What is your sex?

Female _____
Male _____

25. What is your race?

White _____
Black _____
Asian _____
Native American _____
Hispanic _____
Other; please specify _____

26 How old are you?

16-18 years old _____
19-21 years old _____
22-33 years old _____
34-44 years old _____
45-55 years old _____

27. What is your marital status?

Never married _____
Married _____
Divorced _____
Widowed _____
Separated _____

28. What is the last grade in school which you have completed?

29. Additional comments: